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PSYCHOSOCIAL IMPACTS OF UNTREATABLE DISEASE ON PATIENTS AND THEIR MATRIMONIAL RELATIONSHIP

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ABSTRACT

This study was conducted to explore and interpret the impacts of incurable illness on patients and social relationships of partners in Khyber Pakhtunkhwa province of Pakistan. Forty (40) terminally ill patients were selected purposively and interviewed individually (26 male & 14 female patients) by the way of open-ended questions. Several themes were extracted following verbatim transcripts. All the participants clarified the impacts of untreatable illness on their social lives and the positive and negative aspects of their matrimonial relationship. Anger, depression, and desperation were noticeable in the terminal patients. Likewise persistent sadness, bitterness, guilt and loss were common in the patients and alternatively in their partners as explained by the respondents. This research underlines a distinct viewpoint on the damaging influences which terminal illness can have on the marital relationship. However it also recommends how to deal the situation in a positive manner by making adjustments required by the concerned illness. The findings indicate that social scientists need to confess and reply to the incredible psycho-social impacts that serious illnesses and related medical procedures can have on the patients and their families even in this modern age of advance technology. Advance social and psychotherapeutic techniques and socio-psychological support of partners can assist such patients to maintain a balanced spousal relationship and live with a positive life style till death.

Background of the Study

Untreatable disease in a person means physical condition with a higher chance of mortality (Hui, Nooruddin, Didwaniya, Dev, Cruz, Kim, Kwon, Hutchins, Liem, & Bruera, 2014). On the other hand, modern medical technology has proved to be helpful for people with terminal illness. Terminal patients can live longer than expected by adapting to the numerous social, physical and psychological complications as the disease progresses (Altschuler, 1997). Correspondingly, terminal disease also affects the spouse of the patient and the relationship between the partners as explained by Sohlman (2004) that different aspects of the relationship like values, beliefs, communication, and socioeconomic relations are deeply influenced. Positive relationship between the partners which has developed before the commencement of the severity of the illness is affected up to a larger extent as one partner become reliant on the other socially and economically. This phenomenological research is first of its nature which is aimed at investigating the Pakhtun community for socio-psychological impacts of terminal illness on patients as well as on their spouse relations.

Before 1960, the only option for terminally ill patients was a quicker and peaceful death as due to limited medical technology, prolonging of life was not feasible. Belding Scribner, a leading nephrologist made clear that “as long as the struggle for survival was the main issue, emotional and social problems were ignored”. This statement led the researchers to focus the patients for social, psychological and spiritual aspects of terminal illness in their studies (Levy 1996). In this regard, sixty four terminally ill patients were studied by Allen (2003) where different stressors were identified and ranked. Among these stressors, fatigue, physical limitations and social maladjustment were recognized as the three topmost stressors. These three were followed by psychosocial stressors like an isolated social life and uncertain future. Among the terminally ill population, anxiety and depression are well documented phenomena (Burton *et al.,* 2004) however, due to methodological issues the real prevalence is unclear.

A great deal of the research on the issue of terminal illness has paid attention to nursing care, treatment, palliative care and issues of euthanasia. However, only a few have analyzed the familial relationships. In this regard, Anthony (2000) highlighted familial aspect of terminal illness explaining role, changes in life style and spousal affiliation. In addition, such patients face difficult social circumstances and become dependent on their spouses for maintaining a healthy role in their family circles (Lowry & Atcherson, 2001). It is an established fact that many such patients transferred the liability of their care and treatment to their partners once they were brought to home, while only 63% of the patients assisted with the preparation for their own care (Brown *et al.,* 2006). A research study performed on 40 spouses of terminal cancer patients confirmed that for their own productive life style, majority of spouses were dependent on their patients’ satisfaction level (Pevalin & Goldberg, 2003). Conclusively, there is major difference in the level of depression among terminally ill patients and their spouses. However, this conclusion should not be considered as ultimate because a further review of literature indicates that merely one third of terminally ill patients consent to participate in such studies. The current study has focused on data collection from terminally ill patients and the alterations in their spousal relationships as revealed through detailed discussion.

Statement of the Problem

Researches confirm that personal adaptation of spouse is mostly predicted by the patient’s adjustment to terminal illness and hence the marital partnership plays a major role in the care process (Horsburgh *et al.,* 1998). Literally, a very few researches can be found that have studied the dyad relationship in a single research since generally terminal patients and their spouses are focused independently. For instance, Lowry & Atcherson's (2001) studied both patients and their spouses in a single research activity proving the existence of insomnia and anxiety in both patients and partners uniformly just after the announcement of the disease as ‘terminal’. Although patients indicated nervousness of their partners, they declared their marriages to be successful and with few difficulties. Another research proved that 20 %

among partners of such patients face depression, sadness, anxiety and stress (King & Crowther, 2004).

The basic objective of this study was to discover the impact of terminal illness on the patients and their spousal relationships. The reason this study is significant is that there is a deficiency of knowledge about the phenomenological influence of mortal disease on the patients and spousal relationships with psychosocial consequences. It was assumed that the psychosocial assistance from the spouse would facilitate and minimize the severity of the terminal illness although the disease would have substantial physical impacts on the patient as well as marital relationship.

Objective of the Study

This study is based on the following objectives.

- To judge the socio-psychological impacts of terminal disease on the patients
- To assess the influence of terminal illness on matrimonial relation

Plan of Work

This study incorporated the participants who were declared as terminally ill at least in the last six months. Moreover, the participants were required to be married having spouse alive. Patients with acute critical conditions, unable to communicate and having a problem of dementia were not included. Medical facility chosen for this study was Nawaz Sharif Kidney Hospital situated in district Swat of Khyber Pakhtunkhwa. Following the inclusion criteria, 40 incurable patients (24 male patients & 12 female patients) were selected for interview (see table- 1).

Procedures

All the interviews were conducted confidentially for protecting the identity of the patients. Through separate interviews, it was likely to do an open discussion without being influencing others or being influenced by them. Each respondent signed an informed consent before the interview. All the subjects were let free to communicate their views regarding their illness and social relationships.

The transcripts were analyzed by following the Husserlian phenomenological approach. This approach uncovers sense of human experiences through talking to people who are living with the true experience (LoBiondo-Wood & Haber, 1994). Consequently, the purpose of the transcript analysis was to disclose the essential character of the lived terminal illness experiences for the patient by `bracketing' the researcher's preconceptions. As Lubeck and Hubert (2005) explain “The phenomenologist wants to investigate meaning conferring acts which are strictly relative to the specific place, time, circumstances, participants, culture and personal experiences of the respondents”. Previously, research has found that verbal samples include valid catalogs of the person's psychological state in psychiatric and medically ill people (Spector, 2000).

Open-ended research questions were designed to obtain respondents' impulsive experiences. To obtain an actual sense out, all original transcripts were first read two times. Once reaching a consensus by the researchers, themes were taken out in accordance with the phenomenon under thought. Some of the participants were involved again for validation of themes to identify the actual meaning. The researchers made sure that the results were applicable to the associated research population.

Table 1: Demographic and Clinical Information of the Respondents

Demographic/ Clinical Information	Male patients (n= 26)	Female patients (n= 14)
Mean age (years):	41.08	35.7
Gender:	65%	35%
Marital Status:		
Single	0%	0%
Married	100%	100%
Occupation:		
Unskilled	25%	
Professionals	41.6%	8.3%
Housewife	----	25%
Average income (per month):	56,000 PKR	18,000 PKR
Average duration of terminal illness:	1 year	1 year

Results

Numerous notable statements were documented about the impact of terminal illness on the patients' social lives and their matrimonial relationships. Tables- 2 presents example of significant statements and their originated meanings. A female patient described that significant physical limitations are developed due to tiredness, altered temper and a loss role and authority in the family circle. Some other respondents also uttered similar effects, like social limitations and exhaustion.

Table 2: Statements/experiences of Terminal Patients' and their dyadic relationship

Patients' Statement	Extracted Meaning
i. It is astonishing for to be still alive…. I do not know when another episode of illness will strike me.	i. Anxiety was prevalent among patients due to vague health conditions.
ii. I get extremely fed up…… why the people in surrounds are changed so rapidly and surprisingly.	ii. Many unanticipated psychological responses were exhibited by the terminally ill patients (including frustration).
iii. We are living as a couple for 14 years and we have a good time. Except minor difference of opinion sometimes we enjoyed a good life together. This illness has made many problems.	iii. Respondents revealed positive relationship with their spouses with some signs of desperation.

A. The patients' perspective regarding terminal illness and its impacts

The patients’ response was analyzed and various themes were extracted to highlight the impacts of terminal illness on their physical and emotional health.

(i) Vagueness of health status causing anxiety

Majority of the patients were uncertain about their health security as the minimal positive health status was interrupted by episodes of acute illnesses. In this context a respondent stated that:

“I do not see any hope of a healthy life but some way I try to recover as soon as possible. The medical staff is surprised over my living. According to them life is capricious and I do consent with them. As I visit the hospital infrequently and watch those patients who are worse off than me, I start fighting my disease again till next acute episode attack over me. There are infrequent episodes of happiness and sorrow in my life. Now the doctors try to keep me sedated most of the time. This sedation is not helping me that much”.

The connection between fatigue and terminal illness was described by the patients in detail. This was same for them as well as their partners. Another respondent explained that:

“This disease has weakened me a lot. I feel that my lower limbs are not parts of my body anymore. I sit and stand hardly with the help of others. My husband spent most of the day in his shop and when he comes home he has to look after me and the children for hours. This is really a big physical burden for him”.

(ii) Alterations in daily life since the beginning of terminal illness

The relative impact of terminal illness on patients’ lives was discussed by all the respondents in detail. Limitation imposed by the disease leading to social exclusion was a great concern for all. Due to various physical and medical needs all the time, most of the patients were unable to go outside their residence. This situation was faced by all the patients, while reflecting upon this a respondent shared his experiences and told that:

“We want to visit different venues, places and relatives but we need to move different medical equipments and take medicines with us. This is a troublesome which do not let us to move freely. This illness has changed our normal life”.

A number of patients explained changes in earnings due to inability to perform their job. This has led to many life-style changes. Some of them changed their residential location and faced a new physical environment and neighborhood. In this context, field data also show similar results. An extract from interview:

“This was our dream to live in a house owned by us, and luckily we build our own house. We were really happy there. Then I got ill. Now we are living again in a rental house near to the hospital because travelling from far away is difficult for all of us. However living near a medical facility is also an advantage”.

Nearly all of the patients highlighted the harmful impacts of terminal illness, for example financial changes, changes in role, and social exclusion. Among these, social isolation was a major concern as explained by the patients. This was authenticated by field information and a respondent stated that:

“I used to recite the Holy Quran daily and it brings mental satisfaction to me. I do it in a separate place. I do not want to meet people frequently as I used to do it in the near past”.

(iii) Terminality of illness and disturbing responses

Untreatable illness and related medical procedures imposed some physical, social and psychological restrictions on patients. These limitations led to some emotional responses like depression, anger and daydreaming ideas. Some patients wished to enjoy a disease free life for a week and take care of their children. Some patients used refused to cope the impact of the disease and they did not considered them as terminally ill. During interview a respondent also shared similar experience and uttered that:

"My disease is not the fatal one. I have seen patients on YouTube who have undergone liver transplant successfully. I hope I will be better soon".

Many patients did not describe their disease name specifically but called it as 'it' in an angry unconcerned mood while some were living in fantasy ideas of life without disease. This was an idealistic expectation. In similar context another respondent added that:

"I will get better soon InshAllah (if Allah Wills). I have seen some patients who were severely ill and were treated to get healthy. I believe in miracles".

The patients were angry because terminal illness has affected the social and family role of the patients i.e. from independence to dependence. The experiences and answers of respondents were full of anger, annoyance and frustration. An extract from interview:

I am truly frustrated. I was a fine wood worker. I got ill at a younger age. Now I cannot join my friends company. This is happening for the last 08 months.

B. The patients' perspective regarding terminal illness and its impacts on marital relationships

Following the course of data analysis, patients' opinions regarding the effects of terminal illness on matrimonial relationships were organized and represented in the form of separate themes.

(i) Positive features of patients' matrimonial relationships

Respondents expressed hopeful views regarding spousal relationship. Unconstructive remarks were less common among their statements. Most of the patients were in their marital relationship for more than 10 years. All the respondents explained the role of their spouses with respect, sympathy and appreciation. Talking about her husband an interviewee was a bit shy: Analysis of field data also show similar results and a respondent told that:

"We always take care of one another for the last 14 years since our marriage. Now after I got ill, my husband never let himself to be careless or bored".

The patients also talked about the personality and nature of their spouses. According to them some were attentive and soft-hearted, while others were too much worried for them. Some showed a friendly and cordial behavior whereas some were restless. The spousal relationship of many patients was based on intimacy and respect. While expressing his experiences a respondent agreed that:

"Since I got ill, the only major source of my assistance is my wife because she manages those aspects of my illness which cannot be performed normally by someone else".

The patients described the role of their partners as positive and cooperative. Courage, love, care and friendliness were the words used by the patients during the interview. Both male and female patients praised the role of their partner.

(i) Thoughts of liability towards the spouse

Some subjects expressed their feelings telling that their severity of illness has caused physical and psychological burden for their partners. It was found during field interviews and a respondent narrated that:

"He (my husband) performs several tasks at a time like his job, caring me and also managing household activities sometimes".

Similarly, majority of respondents also showed worry about the health of their spouses. This is due the extra workload faced by the partners during the care and treatment process. They also appreciated the partners for the provision of physical and psychological support. Another respondent added that:

"She (My Wife) waits for me all the time before I reached home. She calls me frequently when I am not at home. She never felt her tiredness to me but I can feel how tough her life is".

(ii) Fatigued response of spouse towards ill partner

Some patients explained the altered behavior of the spouses and their changing attitude towards them. Besides, their partners seemed to be overtired and ignoring them sometimes. While reflecting upon this a respondent told that:

"After the commencement of my illness as serious, my wife was extra carful initially. She managed both me and the children very well but with the passage of time my needs were too many to be managed. I felt that she is exhausted to manage everything all the time. I think this is normal for any human being".

Moreover, the ambiguous gratitude of the spouse was explained by the patients. Field information also supported secondary literature and a respondent explained that:

"*Sometimes my husband portrays me as self-centered, demanding and impatient. This is often true when I am in pain or need an immediate help".*

(ii) Spousal relationship failure

Many patients explained loss of physical intimacy and partnership due to terminal illness and it was found that their illness has influenced their relationship and life. An extract from interview:

"It has badly influenced our marital relationship. We both remain too much exhausted to perform daily routine. We are busy in handling the disease and related complications. It has caused physical and psychological troubles which do not let us to take care of our marital adjustments".

The expressions of the patients were such that they thought their life has come to an end since the onset of terminal illness because they used past tense during the interview discussion.

Discussion

This research study focused to unveil the impacts of terminal illness on patients and the matrimonial relationship they have with their partners. The results uncovered a complex interrelation between terminal illness and anxiety, depression, role alteration and emotional disturbances. Although the data showed a combination of both positive and negative reactions of the respondents towards their disease and health status, majority expressed depressing features of terminal condition. This is probably due to severity of illness, co- morbidities, low socioeconomic status and disorganized healthcare system. Alternatively, it could be perceived that terminal illness is itself an unhelpful life event. Such illness leads to negative features like limited social interaction, irritation, anxiety and other key variations in life.

During the interview process it was eminent that the patients were exhausted all the time and unable to do anything and were tired. Our findings like depression, anxiety, social exclusion and insecurity regarding future were similar in nature as found in other researches like by Council on Scientific Affairs, American Medical Association (1996). Terminal illness is an amalgamation of fatal attacks, unpredictable episodes of acute illnesses as well as stability. This multifaceted scenario of health directs the patients towards psychological and spiritual adjustments where they start believing in fate and miracles.

All the respondents expressed their views regarding the impacts of terminal illness on matrimonial relationship. The patients expressed major life-style adjustments since the beginning of their illness. Some of their concerns were failure to do work, to travel and to move to another place with their partners. Hinton (1994) also found some results which highlight similar family issues. Some patients explained that social isolation, loneliness and prolong treatment procedures have affected matrimonial relationship and were their most important worries. Untreatable disease and related complex treatment protocols have pushed the patients to face sadness, anger, and fatigue. Accordingly, their spouses were also regularly aggrieved, fatigued and uneasy.

Unexpectedly, some patients explained their spousal connection as very constructive, lovely, and full of care. The impacts of terminal illness on marital relationships were expected to be complex, negative and uncertain due to associated co morbidities and social detachment. However this study found out that it is not true in every case. Probable conclusion of this might be that they had a consistent conjugal relationship before the onset of terminal illness.

The role of the spouse in supporting health of their partners was acknowledged by the subjects. They accepted that without the help of their partner; treatment and care would impossible. However, the loss of physical intimacy, inequality in partnership and dependence were indicated as hurtful results. Some limitations of this research were differences in the economic and educational status of the samples. Some mystifying effects might be due to the low socioeconomic status and not the disease.

Conclusion

Adopting a phenomenological design, this research study has described the experiences of terminally ill patients and the impacts of their disease on them and their spousal relationship. Life with terminal condition is a fearsome for both the patients and their family members especially their partners. The findings show similar types of concerns for almost all the patients i.e. sadness, anger, hopelessness etc. Similarly the matrimonial partnership has been affected about which the respondents expressed various positive and negative consequences.

Improvement in the socioeconomic status and provision of advance medical facilities can help to minimize patients' afflictions. In addition, familial socio-psychological support and positive dyad relationship can assist such patients to live with a quality life till the death. The suggestions for the sociologists and psychologists are that they need to identify and answer to the incredible psychosocial impacts that serious illnesses and related medical procedures can have on the patients and their families in a modern era of advance technology. This research study provides a platform to the researchers to explore some other aspects of terminal illness. These may include alteration in religious spirituality, parental relationships and economic impacts.

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