8.
Fear of Death: Patients' perceptions of spiritual care during the acute phase of myocardial infarction.

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Abstract

The recovery time from myocardial infarction (MI) to the return to normal life is one of uncertainty and emotional turmoil for the patient and the relatives. Thus, patients facing acute MI, a sudden onset of life-threatening illness, tend to experience anxiety and depression due to fear of sudden death. This sudden onset may serve as a spiritual encounter to the patients whereby patients may reflect on their life, evaluating their rank of priorities in life. Additionally the patients may turn to spirituality as a coping mechanism.

Levels of anxiety and depression can be reduced by effective coping skills such as positiveness towards life, including the use of spiritual coping strategies. The essence of spiritual care is *being* as opposed to *doing* (Piles 1990, Ross 1997, Turner 1996, Widerquist 1991). Thus the role of the nurse and the multidisciplinary team is to help the patient find meaning and purpose in life and have a positive outlook to life.

The aim of this paper is to describe the experience of fear of death of a sample of 53 patients with first acute MI, together with their perceptions of the role of the nurse in the delivery of spiritual care. Recommendations to the nursing practice, hospital management, education and further research are included.

Aims

The aim of this paper is twofold,:
a) to present the findings on patients' perceptions of spiritual care after experiencing the acute phase of their first myocardial infarction, a life threatening illness.
b) to identify any differences in patients' perceptions on spiritual care in terms of their characteristics and levels of anxiety.

Rationale for this research study

My interest in spiritual care was promoted by my clinical experience, as a staff nurse working in ITU in St. Luke's Hospital in 1980's and in several hospitals in UK. While I used to consider the patients' future to be distorted because of his/her chronic illness following the sudden onset of an acute illness such as myocardial infarction or neurological disorder, I was often impressed by the patients' strong will to live, accompanied by a positive outlook to their future.

Very often patients used to transcend their difficulties and reach a higher power, such as having faith in the medical profession or in God, hoping that things will get better. On reflection, I must admit that at times, I was not in tune with the patients' perceptions of their recovery from their illness. Hence, my nursing care might have overlooked the outcome of the spiritual dimension of the patients' coping mechanism.

Consequently, following a personal consultation with two foreign nurse researchers, Prof. Philip Burnard and Dr. Linda Ross in 1998, I decided to explore the spiritual dimension in nursing care. Thus, I took Dr. Linda Ross research question, generated from her study, to explore patients' perceptions of spiritual care as part of a longitudinal research study.

Anxiety and Fear of Death During the Acute Phase of MI

Research suggests that anxiety tends to be common among survivors of myocardial infarction (Conn et al 1991, Thompson et al 1995). This is because patients may perceive their MI as a source of stress beyond their control due to the possibility of another attack and impending death (Webb and Riggin 1994, Lidell et al 1997, Rose et al 1994).

An example is given by a 44 year old male patient with MI, stating,

Waqt l-uġiegħ, ma kontx naf li hu attakk tal-qalb, għax jien, fl-eta' żgħira ta' 44 sena, żgur li qatt m'għaddhieli minn moħħi li kellu jtini attakk tal-qalb. Dak il-ħin bżajt ħafna, għax qas stajt nifhem x'kien dak l-uġiegħ. Ħsibtni se mmut bl-uġiegħ, għax dak tagħfis ġo sidri.......... u uġiegħ f'idejja, u sirt għarqan xraba. Dak il-ħin, ħsibtni se mmut u bdejt naħseb fit-tfal li nħalli warajja u l-mara li tant inħobb u hi tirrispettani ħafna. Ħa ngħidlek ta', imurlek il-qżież kollu li jkollok u malajr tisserja, issib il-mewt ma' wiċċek! (M21)

Moreover, the question of meaning arises in acute sudden illness, when the individual may go through a period of reappraisal and re-evaluation of one's life (McSherry 1996, Burnard 1988). Thus myocardial infarction could force the individual to undertake life review, find meaning and make sense of one's illness and hoping for the future.

Furthermore, in times of crisis such as illness, individuals tend to turn to spirituality (Belcher et al 1989, O'Brien 1982, Reed 1986, 1987). This is supported by the statement from a 57 year old male patient who came to retire in Malta following 40 years abroad.

X'ħin wasalt l-isptar, tatni rasi.... Il-kamra imtliet bit-tobba u n-nurses.... Qalbi għamlet tikk.... Tgħidx kemm bżajt,....... Se mmut, se mmut! Għidt bejni u bejn ruħi! F'ħakka t'għajn, ħajti ġiet quddiem għajnejja....Heq, jiena kont fil-business... kien għad kelli unfinished business.....

U, ara kemm għamlu miegħi n-nurses! Imma jien, dak il-ħin l-aktar li kelli bżonn kien li nqerr....... xtaqt inserraħ qalbi.... Lanqas fis-CCU ma stajt nagħmel dan, għax kont f'kamra ta' bi tnejn. Imbagħad kif qomt fuq saqajja stajt inqerr, u għidt għall-erwieħ! It's a pity li m'hawnx fejn titkellem naqra b'mod personali ġo dan l-isptar! (M14-57 years)

Consequently, literature proposes that illness and hospitalisation may be a source of spiritual encounter to the patient. Thus, since nurses are present day and night with the patients, they are in a position to safeguard the wholeness and integrity of the patient (Forbis 1988, Granstrom 1985, Ross 1997).

Defintion of Spirituality

Spirituality is derived from the Latin word spiritus, spirit, the essential part of the person (Piles 1990) which "controls the mind and the mind controls the body" (Neuman 1995:48). Therefore it infers that spirituality is the vital life force which unifies all aspects of the human being (Reed 1992, Burkhardt 1989, Golberg 1998). Thus it denotes that spirituality encompasses the physical, psychological and social components (Neuman 1995, Colburn 1990, Henderson 1967)

Stoll(1989) summarises the definition of spirituality as 'my being, my inner person. It is one expressed through my body, my thinking, my feelings, my judgements and creativity. Through my spirituality, I give and receive love, I respond to and appreciate God, other people, a sunset, a symphony and spring' (p:6).

Literature suggests that a person who is in tune with this vital unifying force of the spiritual dimension, a more balanced state of physical, mental and social well-being will result. This is because spirituality helps the person to strive for meaning and purpose in life (Orley 1994, Brooke 1987, O'Brien 1982).

Unfortunately, literature has misinterpreted spirituality as being synonymous with religiosity. However, spirituality is broader than religion (Cawley 1997, Nagai-Jacobson and Burkhardt 1989, Burnard 1988). Therefore Narayanasamy (1991) argues that spirituality goes beyond religious affiliation as it strives for inspirations, meaning and purpose in life, even in those who do not believe in any god. Hence, Baldacchino and Draper (2001) assert that spirituality applies to both believers and non-believers, including the presence of different cultural and religious beliefs.

Definition Of Spiritual Care

Spiritual care is defined in the literature, as recognising, respecting, meeting patients' spiritual needs, facilitating participation in religious ritual, communicating by listening and talking with clients, being with the patient by caring, supporting, showing empathy, promoting a sense of well-being and referring to others and clergy (Ross 1997, Piles 1991,Taylor et al 1994) .

Therefore, the essence of spiritual care is *being* as opposed to *doing* (Piles 1990, Ross 1997, Turner 1996, Widerquist 1991). Therefore, the nurse's availability and actual presence to the patient, may help him/her to find meaning and purpose in life situations, by religious and/or non-religious means. Thus, Govier (2000) proposes that nursing care should address the human spirit, both within and outside the context of religion.

Furthermore literature argues that it is not merely the delivery of care which matters, but it includes the heart and the spirit by which holistic care is given (Piles 1990, Younger 1995, Bradshaw 1994, McSherry 2000).

Consequently, the nurse's role in the delivery of spiritual care is prescribed by the International Council of Nurses (ICN-1973) reinforcing the responsibility of the nurse to promote "an environment in which the values, customs and spiritual beliefs of the individual are respected". This is supported by the Maltese code of Ethics for nurses and midwives (1997:3) stating that the nurse is to "recognise and respect the uniqueness of every patient/client's biological, psychological, social and spiritual status and needs".

Research Design And Methodology

This research is part of a longitudinal study conducted in the main local general hospital between January and March 2000. A systematic sample of 70 patients was recruited on alternate basis, aged 40 years and over, capable of participating in an interview and self-administered questionnaires. 53 patients participated, thus having a response rate of 76%.

The three instruments used are as follows,

1. *The Hospital Anxiety and Depression (HAD) Scale*, an established tool developed in U.K. by (Zigmond and Snaith 1983).
    Test retest on a cohort group of student nurses, revealed a Cronbach alpha coefficient of 0.89, thus showing a high internal consistency of the translated tool.

2. *The Nurse's role in spiritual care (N.R.S.C.) questionnaire*
    The N.R.S.C. questionnaire was developed for this study, based on the nursing and social sciences literature and

validated by a panel of ten experts consisting of 5 foreign nurse researchers on spirituality; two English hospital chaplains and two Maltese hospital chaplains and a Theologian.

3. *The Likert form N.R.S.C. questionnaire* consists of 25 statements with 5 categories ranging from *strongly agree* to *strongly disagree.* Test retest statistical analysis of the bilingual version, on a cohort group of nursing students, revealed a Cronbach alpha coefficient of 0.82 which shows an acceptable internal consistency of the tool.

Factor analysis of the N.R.S.C. questionnaire revealed three factors:

Factor 1 : Facilitation of spiritual coping methods.
e.g.   Enable patient to find meaning and purpose in illness.
            Facilitate private/group prayers on the ward.

Factor 2 : Promotion of interpersonal relationships, self-transcendence and achievement of life goals.
e.g.   Assess patient's relationship with relatives and friends.
            Evaluate the effect of illness on the patient relationship with God/others during hospitalisation.

Factor 3 : Enhancing nurse-patient communication and relief of spiritual distress.
e.g.   Spend quality time with the patient to give support and instil hope in illness.
            Allow time for the patient to discuss his/her concerns and worries.

A semi-structured interview schedule was used to elicit the patients' experience during the acute stage of myocardial infarction.

Ethical Considerations

Permissions were granted by the Director of the Institute of Health Care to include the groups of students for test-retest statistical analysis of the instruments. The Chairperson of the Medical Services approved the recruitment of a sample of patients. A written informed consent was obtained from the sample of patients. Since this study is part of a longitudinal study, where data collection was done five times, confidentiality was ensured by the use of coding system to decrease the possibility of identification of patients. Finally, every precaution was attempted to maintain participants' privacy and protect the patients from any physical or psychological harm or discomfort.

Findings

The findings are presented in total, that is how the patients responded to the overall statements, in each of the three individual factors and in specific statements which were found significantly different.

Anxiety (T2 - T5)

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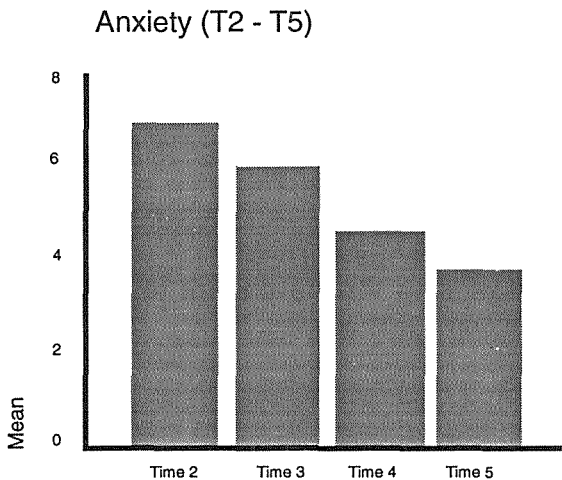
This bar chart shows the highest level of anxiety on transfer to the medical ward (Time 2). However, had this been measured on admission to hospital, the anxiety levels could have been higher as indicated by the quotes which hinted at their frightening experience of impending death.

All patients agreed with the statement, helping patient to see the positive side of his/her life. However, although not significant, it is worth noting that patients with normal level of anxiety scored higher (X=4.74, SD=.45) than those with moderate anxiety level (X=4.30, SD=.48). It appears that the patients may have felt the need for help from other members of the health care team such as the psychologist, clergy or other members of the health care team.
Furthermore, there was agreement by all patients in their overall perceptions of the three factors of spiritual care. Only the variable past history of angina produced a significant difference.

All the three factors were rated lower by those with a past history of angina. This may indicate that the patients with past history of angina, were scared to death by this bitter experience of MI. Since the majority of patients used to smoke, and some had not been compliant with treatment, such as antihypertensive treatment, the patients' guilt feelings may have interfered with the ability of the nurse to help them come to terms with the situation and encourage them to look positively to their future. Additionally, some ethical problems, such as lack of privacy in interactions between patients and nurses or other members of the health care team, may have inhibited a positive response. This is clearly seen by a 54 year old male patient stating,

Jiena ħadt pjaċir ħafna, ngħid għalija li qaluli li se ninżel mis-CCU għal hawn, ġos-sala tal-mediċina. Fejn kont qabel, kien hemm lack of privacy tremenda. Dan minħabba ċ-ċokon ta' l-ambjent! Jiena

ħassejtu jumiljani wisq il-professur, meta quddiem żewġ pazjenti oħra, li kienu fl-istess unit miegħi, ċanfarni, jgħajjat miegħi kemm jiflaħ, għaliex erġajt qbadt inpejjep 20 kuljum. Veru li t-tort tiegħi, imma......(crying) (M62).

One is to note that this patient died the day after the interview, due to a severe complication of MI.

No significant differences were detected between the responses of different age-groups, which ranged from 40 years to 89 years, although the literature suggests that younger patients tend to be less spiritual.This supports the literature stating that during times of distress, the person may turn to spirituality as a means of coping.

Moreover, all patients agreed with statement Facilitate attendance to the hospital chapel/quiet reflection room. However, the females' scores were higher than the males, implying that the females, more than males, may find refuge in reflection time. According to the literature, this may be because the females tend to be more religious in their everyday life. It appears that reflection may help the patient to connect with the inner self, acknowledging one' potentials to overcome the obstacles of illness. Additionally, this quiet time may help them transcend to God, their resource of help and security in life. However problems arise, as described by a 67 year old female patient stating,

Kemm domt l-isptar ma kienx possibbli li mmur il-kappella għax kienet naqra 'l bogħod. Ara kieku kien hawn naqra ta' quiet room biex forsi, wieħed ikun irid jinġabar ftit fit-talb, kieku kont nistaħja. Kieku dil-kamra tkun tista' sservi bħala kamra fejn bniedem ikun irid iqerr, jew ikellem il-patri. Għax kun af, x'jaf min ma ġarrabx! Tara l-mewt ma wiċċek, mhux ċajta, binti. Għal dawn l-affarijiet m'hawn xejn privatezza, ħlief għal dawk il-pazjenti li jinżertaw f' single room. (PF6)

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Consequently this finding reinforces the need for privacy in hospital and the need for a quiet room to be introduced in each floor of the new hospital as is being currently introduced in foreign hospitals, such as Leeds State General Hospital in the United Kingdom.

Finally, the response to "Who do you think should be responsible for providing spiritual care? It was found that the majority of patients pointed out that spiritual care is not only the nurse's role but the role of all the members of the multidisciplinary team, that is nurses, multidisciplinary team, chaplains, patient, patient's family, friends and personal spiritual/religious leader.

Therefore, further research is suggested to explore the role of the health care team to explore their perceptions about spiritual care and to compare their responses with those of the patients. This finding suggests the importance of the caregiver to build therapeutic relationships with the patient through their availability, sensitive handling skills, understanding patients by listening and respecting them and accepting them as they are in their vulnerability during their distress of illness.

Conclusion And Recommendations

1. Since the essence of spiritual care is *being as* opposed to doing (Piles 1990, Carson 1989), it is suggested that nurses commit themselves to reflect on their care as well as increasing their self-awareness to be able to meet patients' spiritual/holistic needs.

2. While considering the complexity of the spiritual dimension in patient's care, the provision of quality time of the nurses and the multidisciplinary team, including the clergy, is recommended. This will help the patient to relieve the

current and future stress of illness enabling him/her to find meaning and purpose in life.

3. The nurse's role is to work in a team to meet patients' spiritual/holistic needs and not simply referring them to the hospital chaplain. To enable optimum holistic care, the curriculum of the nurses and the multidisciplinary team is to include education on spiritual care.

4. Patients' perceptions of the nurse's role in the delivery of spiritual care appears to incorporate the other members of the multidisciplinary team. Thus further research is suggested, amalgamating the quantitative and qualitative research designs, to explore the perceptions of the nurses and the different members of the health care team and compare these findings with those of the patients. This may provide an insight into the nurse's role and the patients' preference for specific interventions of spiritual care.

5. The Management of the new hospital is recommended to reserve a ounselling room in each ward where the patient can confide in privacy. Additionally, a quiet reflection room in each floor by the wards is to be introduced, to provide the patient with an appropriate place for reflection and prayers.

Hopefully, after seeing what the patient had to say, through their experience of such a life-threatening illness of MI, the responsibility now falls on us. As members of the multidisciplinary team, we are to listen to the voice of the patients and try to implement spiritual care in order to help the patient to find meaning and purpose in their life.

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