

# **Patients' perceptions of information-giving during hospitalisation.**

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## **ABSTRACT**

This cross-sectional research study is part of a longitudinal study which was conducted in the main general teaching hospital in Malta. The aim of this study was to explore patients' anxiety during the recovery period and their perceptions of information-giving during hospitalization. A systematic sample of 70 patients were recruited in the Coronary Care Unit (CCU). Both quantitative and qualitative data were collected on patients' transfer to the medical ward from CCU, between July 2000 and March 2001.

Anxiety and depression was measured by the Hospital Anxiety and Depression scale (Zigmond and Snaith 1983). Patients' perceptions of information-giving by the nurses and multidisciplinary team (MDT) were explored by face to face interview during the first 48 hours of their transfer to the medical ward.

Findings revealed that patients rated themselves within the normal (0-7) and mild (8-10) range of anxiety. This may be due to the threatening experience of myocardial infarction (MI), related to the uncertainty in life. However, anxiety may be considered as an effort to adjust to their new life style. The interviews revealed lack of information from the MDT, including the nurses. Searching information about the severity and progress of their illness was perceived as a means of coping and adaptation to their new lifestyle following MI.

This paper recommends further research in order to increase awareness of the nurses and MDT so as to bridge the gaps in the current practice identified by patients.

## Introduction

My clinical experience as a staff nurse and the two research studies on patients' participation in care conducted in Malta (Baldacchino 1992) and the United Kingdom (Baldacchino 1993), triggered me to explore the factors, such as information giving on rehabilitation, which may contribute to stress and coping with illness. Research demonstrates that the MDT, including the nurses and midwives, tend to neglect the informational needs of patients (Thompson 1989, Havik and Maeland 1990)

According to Maltese code of ethics (1996),

*Nurses and midwives should, within their sphere of responsibility, give adequate information to the client in relation to his/her condition and to treatment options, in terms which he/she can understand..... The extent of information has to be adapted according to how much the individual patient wishes to know. ( No. 1.5. : 8)*

The concept of giving tailored and sufficient information is in accordance with Florence Nightingale's recommendation stating, that the environment should do no harm to patients.

Consequently, Henderson (1969) proposes the unique function of the nurse, that is, to assist the individual to perform those activities, contributing to health or its recovery that he would have performed unaided if the patient had the necessary strength, will or knowledge.

The aim of this paper is to present the perceptions of a sample of 70 Maltese patients regarding information-giving in hospital, on their illness and rehabilitation, following their first acute myocardial infarction (MI).

## THEORETICAL BACKGROUND

### 1. **Orem's Theory of Care (1985): The educative-supportive mode of care.**

Orem identifies several factors which may influence self-care such as, motivation, knowledge, skills, confidence and limited range of behaviour. The educative mode of care identifies the nurse as being the main resource of information to enable the patient to participate in his or her own care. The nurse helps the individual by developing appropriate learning environment to enable the individual to learn new skills. In doing this, the nurse guides, directs, instructs and supervises the individual to achieve self-care. Eventually, this support will assist the individual to achieve independence.

### 2. **The Cognitive Stress-coping Theory (Lazarus and Folkman 1984): Interpretative mode of coping.**

During a crisis situation or illness, the individual identifies whether the crisis is threatening or challenging (*primary appraisal*). Also, the person determines whether the available resources are sufficient to cope with the situation (*secondary appraisal*). Consequently, the individual may seek information in an attempt to adapt to the new lifestyle (*secondary appraisal*).

## Literature Review

Research suggests that anxiety tends to be common in patients with illness, such as myocardial infarction (Roebuck *et al.* 2001, Thompson *et al.* 1995). This is because patients with MI face both an acute life-threatening illness and the potential for living with a major illness (Thornton 2001, Kim *et al.* 2000). Additionally, the patients' whole sense of meaning and purpose in life is at stake (Walton 1999, Burnard 1988). Illness may make the person undertake life review (Baldacchino 2002, Walton 2002, Simsen 1985) which may lead to a change of lifestyle. However, it is argued that adaptation to a new lifestyle may

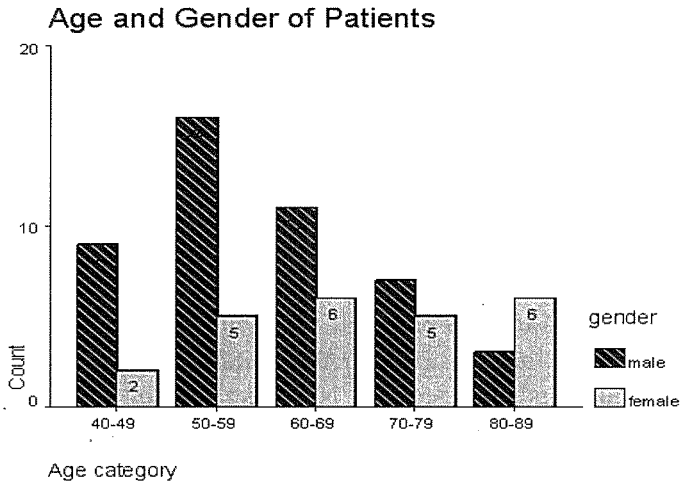
occur only if the person is surrounded by an educative and supportive environment (Roy 1986).

Consequently, since nurses are present day and night with patients, they are in a position to be the main resource of information during hospitalisation. Additionally, the nurse can liaise with other members of the MDT, such as the medical doctors, dieticians, and others to help them adapt to the new life style following illness (Stewart et al. 2000, Havik and Maeland 1990, Thompson 1989).

### Research Design And Methodology

This descriptive research is part of a longitudinal study conducted in the main local general hospital. A systematic sample of 70 patients was recruited on alternate basis, aged 40 years and over, capable of participating in interviews and self-administered questionnaires in Maltese.

**Figure 1: Systematic random sample of patients with first acute MI**



It is noted that the majority of patients (66%) were males (n=46 males, 24 females) and most of them were middle aged between 50-59 years (n=21) (Figure 1).

The two instruments used to assess anxiety and patients' perceptions of information-giving were:

- a) **The Hospital Anxiety and Depression (HAD) Scale**, an established tool developed by (Zigmond and Snaith 1983) with a history of survival of translations into several languages, such as Arabic.

Due to the problem of illiteracy in the Maltese population, the Hospital Anxiety and Depression scale was translated into Maltese for improved comprehension. According to the Malta Central Office of Statistics (1999), only 16.4% of the Maltese population were reported able to read basic English, whilst 46.7% were able to read Maltese. Reliability test-retest statistical analysis revealed satisfactory value of Cronbach's alpha of 0.73 for the Maltese version.

- b) **A semi-structured interview schedule** was devised for this study to elicit patients' experience in hospital during the recovery stage of their heart attack. The interview was conducted by me on patients' transfer from CCU to a medical ward. Two of the questions were oriented towards the information they received as part of their rehabilitation. Another question addressed the role of the nurse in information giving while in hospital.

- Kif qed jiehdu hsiebek in-nurses f' din is-sala tal-medicina?  
*In what ways are the nurses taking care of you on the medical ward?*
- X'informazzjoni tawq fuq kif ghandek taddatta lilek innifsek biex tirpilja minn dan l-attakk tal-qalb?  
*What information were you given on how to adapt yourself following your heart attack?*

- Kif tahseb li n-nurses jistghu jghinuk l-aktar biex ittejjeb il-qaghda tieghek?  
*How do you think the nurses can help you best to improve your condition?*

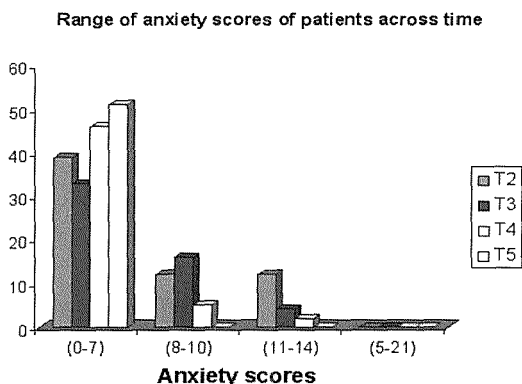
This data was collected on patients' transfer to the medical ward, between July 2000 and March 2001. Each interview was audio-tape recorded and transcribed for better interpretation of data.

### Ethical Considerations

Permission to conduct this research was granted by the Chairperson of the Medical Services and Director of nursing services. A written informed consent was obtained from the sample of patients. Since this study is part of a longitudinal study, confidentiality was ensured in the use of coding system to inhibit identification of patients. Finally, precautions were taken to maintain participants' privacy and to protect them from any harm or discomfort.

### Findings And Discussion

**Figure 2** shows that on transfer to the medical ward (T2), 61.8% of patients (n=39) were found within the normal range of anxiety level



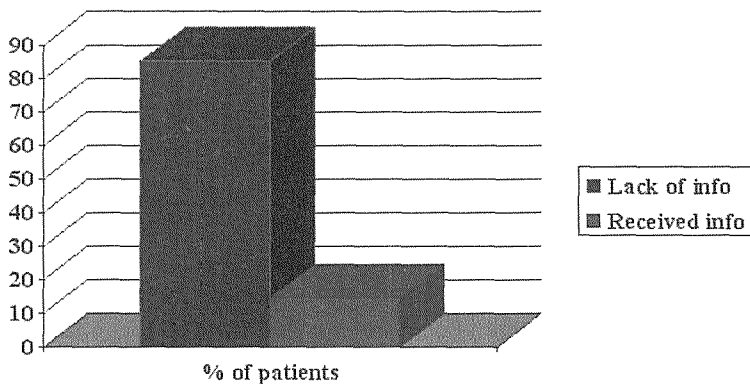
**Figure 2.** Range of anxiety scores of patients across time.

(0-7). This was further sustained by 62.3% of patients (n=33) on discharge home (T3) and 86.8% (n=46) at 6 weeks after discharge (T4). Three months after discharge all patients were within the normal range, (T5).

These findings are congruent with results of research where patients rated themselves within the normal (0-7) and mild (8-10) range of anxiety during their recovery period (Terry 1992, Chiou *et al* 1997). This is possibly because anxiety may be associated with threat, such as uncertainty about the cardiac health status and feelings of vulnerability (Havik and Maeland 1990, Stewart *et al.* 2000). However, according to Bowman (2001), anxiety may be considered as an effort to adjust to the situation. One of the strategies sought by patients was searching for information about the severity and progress of their illness and ways of adapting themselves to a new lifestyle.

### Figure 3. Information-giving to patients as perceived by patients

Unfortunately, findings revealed that the majority of patients (n=60, 85.3%), perceived lack of information-giving from the MDT, including the nurses. One is to note that during this data collection, an occupational therapist, working on a part-time basis, took the initiative to visit patients with MI individually while on CCU. A list of *do's and*



*don'ts on rehabilitation* were explained to them individually. However, these patients felt the need to have these explanations in the presence of their spouse for better comprehension. Moreover, they expected further information-giving from the nurses and MDT on the medical ward, on their way to discharge. Thus, the need of family participation in the rehabilitation process is consistent with the literature highlighting its successful impact in the recovery period. (Thompson 1989).

For clarity purposes, patients' quotes are presented in Maltese, as Maltese language can be highly explicit about the role of the nurse and MDT as information givers, as stated by this female patient,

*'In-nurses m'għandhomx ċans wisq biex joqogħdu jtkellmu naqra miegħek u jfehmu xi jkun qed jiġri minnek. Ara bil-lejl iva, jekk jarawk imqajjma, jiġu u jaraw kif jistgħu jgħinuk u ġieli qagħdu jtkellmu naqra miegħi. Kienu jissollevawni ħafna meta kienu jiġu hdejja..... Jiena għadni żgħira u barra l-attakk tal-qalb, messitni wkoll id-Dijabete. Qas naf fejn se nagħti rasi! (crying)..... S'issa qed inħalli f'idejhom, imma nispera li xi nurse jew tabib ifehmuni sewwa x'għandi nagħmel għal meta nsib ruħi waħdi d-dar..... X'waħda din ħajti mbiddlet mill-lejl għan-nhar! (crying)' (F1, 51 yrs).*

This patient had a hectic life before the onset of this illness which threatened her life and interrupted her independence. This interview was carried out 48 hours after her transfer to the medical ward from CCU where she had stayed for five days. According to the literature, education of patient should start from day one of hospitalisation. It is well known, that rehabilitation of this middle-aged patient entails the contribution from various members of the MDT. Therefore, one would wonder why this patient, had not received any formal information by the seventh day of her admission, in preparation for her discharge. This may be because there is no *formal rehabilitation programmes* in hospital for patients with MI or Diabetes.



Furthermore, the nurses and MDT may take things for granted as expressed by this male patient:

*'Ma nistax ingerger minn nurses. Kienu jiġu jqassmu l-pilloli u anke jittestjawli d-demm għaz-zokkor. Għalkemm qaluli li kelli attack tal-qalb, imma x'wa'da din, tibqa b'xiber imnie'er għal xi informazzjoni li jistgħu jagħtuk. .... Ma jgħidulek proprju xejn, donnhom jistennew li aħna nafu kollox. Kif ngħidlek jien, iħalluk lampa stampa! (M04, 59yrs)*

Additionally, the paternal role of the medical team may hinder patients' participation in decision making about their own care as illustrated by this male patient prior to discharge,

*'Deherli li kont smajt il-professur li wara jumejn li ġejt f'din is-sala, kellu jibgħatni d-dar. Imma tqarraqt għax dewwimni ġimgha hemm. .... Baqgħu sejrjn bl-investigazzjonijiet. Għall-ewwel jiena ħsibt li hemm xi haġa ħażina. Santa Marija, lanqas jgħidulek xejn, iħalluk fil-ghama. .... Jaħasra n-nurse ma kienx mal-Professur meta ġie jarani, għax kieku ma kontx niddejjaq nistaqsih kif u x'fatta meta narah wara. Madankollu, il-'head nurse' ġieli ġie jitkellem miegħi, imma aktar tkellimna fuq in-Naxxar [fictitious] fejn noqgħodu, milli fuq dak li xtaqt inkun naf għalija personali'. (M02, 68yrs)*

This patient was expecting the nurse's assistance during the ward round. This denotes that the nurse is still considered by patients as their advocate in order to clarify misunderstandings during communication between the patient and medical team. Thus one would ask:

- Why is it that the nurse's presence is not available to patients during these visits?
- Is it simply because the wards are overloaded by patients? Or

- Perhaps because there are too many medical firms on the ward, with too many doctors attending patients at one time? Or
- Is it because the nurse has resigned from her advocacy role in the care of patients? Or
- Is it because the nurses are taking for granted the following Maltese code of ethics statement,

*'Patients who wish not to be told certain things, and who prefer to leave everything in the hands of their carers, whom they trust to do the best for them, should have their wishes respected'.*  
(No 1.5., 8)

On reflection, one can say, that whenever we, as nurses, have a close relative in hospital, our preference would be to be present during the ward round. This is to ensure that we won't miss any useful information, for the benefit of our beloved relative. Therefore, why don't we try to assist patients as if they are one of our closest relatives?

Moreover, the findings revealed that patients received information about their progress *only* when they or a member of their family, took the initiative themselves to ask specifically for the information from nurses or MDT, as expressed by this male patient,

*'Sew tas-sala fejn kont u sew t'hawn, mhux għax jagħtuk xi nformazzjoni ta' l-għaġeb....Anzi mill-inqas!...Jekk ma tistaqsihomx int, m'hemmx ans li tiegħu xi informazzjoni fuqek innifsek minn għandhom'.*  
(M10, 51yrs).

This was echoed by another male patient with a higher level of education stating,

*Sincerament ma tantx nara differenza wisq bejn is-sala li kont fiha u s-sala tal-medicina. F'wahda għandek nurses b'moħħ*

*tekniku għall-aħħar u fis-sala tal-medicina jidhru li ma jistgħux ilaħħqu max-xogħol kbir li għandhom minhabba li hemm numru kbir ta' anzjani. Il-problema fit-tnejn qegħda, li jekk ma tistaqsix inti, lanqas biss jindenjaw ruħhom li jgħidulek x'riżultati ġew, wara li jkunu ħadulek id-demm jew xi jfissru xi investigazzjonijiet li jkunu saru fuqek. Huwa l-pazjent għandu bżonn isaqsi, ngħid jiena??? Mind you, jiena saqsejthom ta, bla waqfien, għax jien, irrid inkun naftejn jien'*  
(M22, 58 yrs).

This patient appeared to be assertive enough to seek information himself on his own initiative. However, literature asserts that the nurse's role is to assist patients, to obtain the necessary information, according to the policy of the hospital, to enable adaptation to the new life situation.

Unfortunately, one is to note that the nurses might not be considering themselves as a resource of information which may help in relieving anxiety. This was expressed by several patients stating,

*'Hawn, fis-sala tal-medicina, hawn bruda tremenda, orrur! Kemm jagħtuk the 'bear minimum'. Fis-sala l-oħra n-nurses kienu jaqduna b'interest kbir, imma hawn, għax jarawk forsi fuq saqajk, jaħsbu li inti 'self-sufficient'. Imma, Alla jaf minn x'hiex tkun għaddej. Għalhekk jeħtieġ li n-nurses ma jqisux bħala xogħol dak ix-xogħol ta' l-idejn biss, bħal pereżempju, jqassmu l-pilloli. .... Imma tajjeb li jiddedikaw xi ħin biex jirkellmu mal-pazjenti. Jiena taf x'qed ninnota li l-ftit ħin li jkollhom free n-nurses jingabru ħdejn id-desk, jew jaqraw il-gazzetta jew ipaċpċu bejniethom. .... Eh jaħasra, kemm jistgħu jgħinuh pazjent, kieku kellhom isibu naqra ħin biex joqgħodu jirkellmu miegħu halli jgħinuh jiċċara xi diffikultajiet qabel ma johrog mill-isptar'.*  
(M10, 51 yrs)

Thus, nurse-patient communication appears to be considered by patients as a means of support to cope with their illness, and a stepping stone to ask the necessary information, as exhibited by this female patient,

*'Forsi qed nistenna ħafna minnhom! Għax kieku x' se jitilfu kieku jiġu naqra ħdejna u joffrulna tbissima? Tbissima tan-nurses qisha fjamma tixgħel! Kieku forsi, naslu ngħidulhom x' inhu jinkwetana u nistaqsuhom x' għandna bżonn nagħmlu biex ma jergax jaqbadna dak l-ugieġħ. Anke kieku kellha tiġi ħdejk, taqbadlek naqra jdejk u tgħidlek bongu, kif inti? Ukoll tagħmillek kuraġġ u s-salib tħossu eħfef. Unfortunately, minn dan, frit li xejn isir. ... Imnalla nitkellmu bejnietna l-morda, għax hekk ngħinu lil xulxin mill-esperjenzi tagħna, sirna qisna familja f'qasir żmien. Barra minn hekk, imnalla li t-tfal marru jkellmu l-professur privat, għax hekk naftejn jien f'saħħti'. (F45, 82 yrs).*

This statement exhibits the Maltese culture whereby patients and their family may use various ways and means to obtain the necessary information about the patients' health and rehabilitation at all costs. Through experience from this study, I could realise how much patients appreciated the fact that at the end of my visit for data collection, I allowed some time for their queries and also referred them to the respective consultations, such as dieticians, physicians and radiographers.

Finally, the factors pointed out by patients, such as reluctance of MDT to give information to patients, work overload and time constraints, may inhibit the process of information-giving in hospital. However, it could be argued that several other factors may still be concealed, such as hospital policy and reluctance or unwillingness of MDT to give information. Thus, to overcome this weakness, it is suggested that nurses and MDT 'get into the patient's skin' (Henderson 1969) so as to empathise with patients' needs and problems.

## **Recommendations**

Current assessment of patients by the MDT may recognise a fraction of their informational needs, just the tip of an iceberg. Hence, formal rehabilitation programmes are recommended to equip patients with the necessary information to enable them to adapt to their situation.

Moreover, further research is suggested to increase awareness of the MDT on the importance of information-giving to patients by:

1. replication of this study on patients with other diseases.
2. conducting a comparative study, whereby the informational needs expressed by patients, are compared to those, as perceived by nurses and MDT.

Finally, understanding by the nurses and MDT of the importance of information-giving to patients will pave the way towards change of attitude. This will enable patients to rehabilitate themselves to the new lifestyle with relief of anxiety. It is well known that the construction of the new hospital, *Mater Dei*, is at an advanced stage. However, I hope that reconstruction of nurses' attitudes be promoted by further education in order to bridge the gaps identified by patients and to actualise information-giving in care, which is ultimately the right of the patient.

## **Acknowledgements**

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