REVIEW ARTICLE

Information to coronary disease patients

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Abstract

Background : During recent decades providing information to coronary disease patients has received a great of deal of attention by health professionals since it is showed to associated with optimal advantages.

The aim of the present study was to review the literature about the factors that influence the provision of information to coronary disease patients.

Method and material: The method of this study included bibliography research from both the review and the research literature, mainly in the PubMed data base which referred to the provision of information to coronary disease patients. The research covered the period 1997-2011.

Results : According to literature patients need information about their illness, its' care or its' complications. Moreover, they frequently need information about daily activities and practical or financial issues. Demographic or clinical factors are held responsible for adequate provision of information. Equal important factors are the following : source of information, discharge planning, address of patients' problems in daily living, psychological distress, health proffesionals' perception of what patients need to know about their health, involvement of care-givers in the therapeutic regimen and effective communication between patients and health professionals. Information including assessment of patients' learning needs and their readiness to learn is one of the key interventions in nursing process. Development of individualized cardiac information interventions during hospitalization and follow-up clinic visits is a matter of vital importance.

Conclusions : It is widely accepted that providing information to cardiac patients is associated with many benefits since it promotes health care decision-making, encourages patient's participation in treatment process, enhances adherence to medical recommendations and prompts modification of health related behavior

Keywords: Information needs, coronary disease patients, in-hospital information, information in secondary prevention

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The need of information

he need of providing information to patients consists one of the basic principles concerning the rights of the patient. This need came to the front line of medical treatment several decades ago in the late 1960's and early 1970's, when started a shift from "paternalism" where the doctor was the only person to provide information about the disease towards enforcement of patients' participation in the therapeutic regimen. Afterwards a notable change took place in both the quality and amount of information provided by physicians. Initially, the method of accurate and elaborate information had been widely applied in the United States of America, where the doctor-patient relationship was determined by the principle of patients' "autonomy". Unfortunately, even nowadays it is not rare that health professionals have the tendency to adopt "paternalistic model" of care, where the information is filtered and the full truth is hidden thus leading patients to suspicion and doubt about the necessity of treatment or to insecurity about the provided care.¹⁻³

Interestingly, providing information has been considered as a key component of disease treatment that promotes health care decisionmaking and encourage patient's participation in treatment process. Accordingly, information enhances adherence medical to recommendations and prompts modification of health related behavior. The most common information needs include the nature of the disease and related risk factors, medication, dietary intake, psychological concerns, physical activities and management of stress and symptoms. 3,4

Information significantly contributes to the improvement of patients' psychological well-being and increases their satisfaction by the provided care. The more information patients receive, the more satisfied they feel about their ability to cope with the consequences of disease after discharge. On the other hand, satisfying patient information needs is important for health care improvement. $^{\rm 4-6}$

According to the literature several barriers undermine the significant role of providing information to patients such as non availability of time and personnel, poor organization of health services and the nature of the event (acute or chronic). ^{4,7-9}

The fact that patients have become more active, assertive consumers of health care creates the demand of understanding their self-perceived information needs and requires taking into account all subpopulations (elderly, ethnic minorities, seriously ill or disabled) as well as spouses or partners.^{1-3,7}

Factors associated with the provision of information

Coronary artery disease consists the major cause of morbidity and disability in many developed countries, globally. During recent years, due to the increase in life expectancy of coronary disease patients, the interest of health professionals has turned to the assessment and the fulfillment of their needs including the need of information.^{3,8,9} Information needs rank as the highest priority in most studies of the self-perceived needs and concerns of patients with coronary artery disease. The need for information is not a static process but rather varies according to the disease progression and requires constant reassessment. ⁸⁻¹¹

Timmins et al.,⁸ supported that information need is not merely a gap in knowledge that can be satisfied but it reflects "what" the patient wants to know by health professionals in order to cope effectively with the current situation. Therefore, the first step is to ascertain individual patients' informational needs throughout all phases of disease and recovery. Interestingly, patients just not need general information but patientcentered information. Individualized information allows health professionals to include patients in the planning of care thus enabling them to actively participate in their therapeutic

regimen.^{3,8-11} Bergvik et al.,¹² showed that nurses found the patient-centered approach particularly useful in situations when patients often ask questions, experience difficulties in expressing their worries, frequently complain or when spouses express worries.

Research illustrates, that several factors are held responsible for the provision of effective information. ^{1-3,8-11} Demographic and clinical characteristics influence the need of information such as the gender or the nature of cardiac event. al.,¹³ showed that content of Kattainen informational support is different for male and female patients before and after the coronary artery procedures. Women following percutaneous transluminal coronary angioplasty needed more informational support than men before procedures while men needed more support afterwards. Furthermore, Lauck et al.,¹⁴ showed that individuals undergoing angioplasty reported less information needs for the reason that they had the tendency to underestimate the severity of disease due to the short timing of the procedure and hospitalization or the immediate improvement of symptoms and return to previous activities. Following this line of thought, Campbell et al.,¹⁵ showed that approximately 38% of patients believed that no longer suffered from coronary heart disease.

Patients frequently need information not only about the disease and its' treatment but also for other more practical problems associated with everyday activities or even financial issues.^{6,11} Scot et al.,⁷ showed that the most important category of information need was that about risk factors, followed by information on cardiac anatomy and physiology, medications, and physical activity. <u>White et al.,¹⁶ showed that the most common information needs are those about medicines</u>. Timmins⁸ stated that information needs differ according to the process of disease and particularly in the early stages of recovery the most important cardiac patients' learning needs

'psychological factors' are or 'emotional response'. The same researcher claimed that patients appear to prioritize information that is survival including related to symptom management rather than broader lifestyle issues such as exercise and diet. Surprisingly, physical activity, consists an area on which patients place a low priority, though physical activity may be crucial to their overall well being and survival. Similarly, an earlier study conducted by Czar et al.,¹⁷ showed that learning needs that affect survival are the most important at hospitalization and follow-up clinic visit. Smith et al.,¹⁰ illustrated that myocardial infarction patients within 72 hours of their intended discharge had needs related to medications, disease complications and physical activities.

Effective discharge planning system that integrates information is critical in ensuring the quality of care. Wong et al.,¹⁸ highlighted absence of standardized hospital discharge planning in public health sector as well as lack of communication and coordination among different health service providers. Theobald et al.,¹⁹ also showed that patients following heart surgery recommended strengthening discharge planning with more accurate information about recovery and support so as to anticipate fluctuations in health and wellbeing. The same researchers also showed that most important issues concerning period after discharge was the need for postoperative physical and lifestyle adjustments, financial implications of surgery and support including telephone support or community patient networks. More strikingly, Scott et al.,⁷ supported that patients frequently report demand for more information during hopsitalization so as to avoid poor apprehension to the implications of cardiac event or for the way of managing their lives after cardiac event. Doering et al.,²⁰ demonstrated that patients are in need of adequate information about their physical and emotional state because they wish a smooth

transition to home and consequently. Pieper et al.,²¹ showed that unmet discharge needs may contribute to poor patient outcomes and frequent readmissions. Ensuring that individualized patients' information needs are adequately met remains a key focus during hospitalization and cardiac rehabilitation.

Inadequate discharge planning does not seem to be the only reason held responsible for unmet information needs but also the duration of hospitalization seems to be significantly associated with inadequate information. Smith et al.,¹⁰ claimed that shorter hospital stays minimize the opportunities for nurses to provide pre discharge information to patients. Indeed, the modern trend for early discharge, is acknowledged as a great impetus for provision of information since it reduces the time spent by health professionals. Interestingly although, patients with shorter hospital stays may not report receiving less information during their stay, however missing information after returning home was associated with a shorter hospital stay. This may indicate either that information was delivered at a time when patients were unable to absorb it or that the need for information increases when the patients are left on their own to handle their problems. Another possible explanation could be that long hospitalization is associated either with more seriously ill patients that demand further or more intense treatment including examination or interventions or with patients being in need of an extended recovery period. According to Scott et al.,⁷ shorter hospital stays create the demand for more responsibility at rehabilitation and secondary prevention after cardiac event. Hanssen et al.,²² indicated that the ultimate aim of informing patients after myocardial infarction at recovery time is a longterm improvement of their lives through modification of risk factors such as hypertension, obesity, diabetes, physical inactivity, etc.

The source of information has been a matter of controversy for several decades with the doctor to be the main key source of information and rarely the nurse. Indeed, it is not completely accepted whether in clinical practice nurses as an interdisciplinary team are best suited to provide information. Scott et al.,⁷ demonstrated that patients preferred physicians over nurses as information givers. The same researchers also claimed that patients may fail to acknowledge nurses as valid informants if they do not recognize the provided information as an important one. Furthermore, differences are also noted in regard to gender with women preferring the physician and men preferring nurses.

Moreover, according to Moret et al.,²³ discrepancies are showed in transmission of medical information to patient as perceived by physicians and nurses. Nurses considered that they provided information about diagnosis explanations, tests, investigations, benefits and risks of treatment, in addition to doctors whereas doctors considered that were the only to deliver the information.

Effective collaboration and communication am ong health professionals is essential so as to avoid providing conflicting or unnecessary information that frequently lead to ambiguities thus increasing patients' stress.²²⁻²³

Other potential sources of information are books, articles, participation in conferences, lectures, brochures mass and media such as television, radio and the press. In recent years, medical information retrieval by internet has been significantly increased. Indeed, internet is an important mean that provides in short time, conveniently and privately health-related information thus offering the opportunity for better-informed decision making and more actively participation in care. More than 70% of internet users report that retrieval of health information may influence decision about treatment. However, there are some obstacles in internet information such as patients being either unfamiliar with new computer technologies or deprived of computers because of the cost.²⁴ Leaffer et al.,²⁵ claimed that patients over 69 years old used internet to assume an active role in their

personal health care. Scherrer et al.,²⁶ showed that in a group of patients waiting for cardiac surgery internet-based information and education increased social support, decreased anxiety, improved lifestyle and facilitated positive attitudes towards the impending surgery compared to other traditional methods of medical-education. Therefore, in the field of cardiac surgery adequate retrieved medical information by internet may increase patients' knowledge about surgical techniques.

The shift in the role of the patient from passive recipient to active consumer of health information represents a new era of interest. Interestingly, this turn exerts up to some extent an influence either positive or negative on the relation between patients and health professionals. More in detail, McMullan et al.,²⁷ according to health professional usually feel threatened by the 'Internet informed patient' who responds defensively by asserting their 'expert opinion'. On the other hand it is important for health professionals to acknowledge patients' search for knowledge and guide them to reliable health information websites and collaborate in analysing the information. Jones et al.,²⁸ supported that both information seeking and answering patient information requests consists а nursing knowledge work.

According to Murero, et al.,²⁴ Internet may be a powerful tool for improving the health-care decision-making process, however deficiencies in information could negatively influence consumer decisions. Therefore, significant concerns are raised about potential misinformation including quality, credibility and origin of available healthrelated information. There is a growing need for widely accepted criteria that can form the basis for publication of medical material on the Internet.

Regarding the extent of information, patients should be fully informed by health professionals about medical procedures, potential risks or

complications, alternatives solutions, possible recovery time and other medical, social and economic factors that may influence therapeutic regimen or decision making. In this framework, the patient is encouraged to ask questions, since some information is immediately understandable whereas others need some repetition.^{29,30} Scott et al.,⁷ demonstrated that the method of interview which is determined as a conversation with a purpose offers a practical, valid and responsive method for cardiac patient information-giving. This method offers the opportunity to openly explore the patient's information needs and give answers directly. In addition to this method, questionnaires are the most widely used tools especially in large surveys due to the low cost and their ease in apply however, they are subjected to recall bias, thus validation studies should be conducted in order to determine their validity and reliability. More in detail, they are also popular in assessing individual patient's information needs since they provide a context to report all informational topics. 7,31

Effective information about the disease presupposes creating such an environment that enhances comfortable atmosphere and reduces any emotional burden to patients. Another issue that needs elaborate assessment is ensuring appropriate and sufficient time for information especially when the patient is receptive to the amount of provided information. Furthermore, the use of clear and no medical terms is extremely beneficial in patients who fail to understand scientific information. **Re-evaluation** of apprehension of acquired knowledge is also essential mainly to the elder or those of low literacy level. Scott et al.,⁷ supported that information should be accurate, relevant and at patients' own level of understanding and age. Indeed, level of education may be responsible for the lack of understanding medical instructions or the reluctance to search more information. According to Paul et al.,³² educational level reflects the ability to comprehend written information, while poor visual acuity limits the benefit of written materials. Johansson et al.,³³ claimed that the way patients learn mainly depends on their own attitude and motivation. New knowledge cannot be received passively but is of vital importance the learner's awareness of his or her own part in learning.

Communication is essential for the effective between health professionals and relation patients and determines the extent of cooperation of the two parties. It is well known that both diagnosis and treatment receive a great deal of attention whereas the way of disease announcement and the possible consequences that disease imposes on patients' lives is frequently under-estimated. Enhancing awareness about the importance of information would benefit thousands of cardiac patients around the world. Lack of adequate information results in growing dissatisfaction of patients, increasing and is responsible for medical complaints malpractice. It is estimated that 70-80% of health professionals' referral to courts concerning the health professional-patient relationship or information problems and poor communication. 34.35

Beck et al.,⁵ claimed that enhancing information involves attention to the following listening, parameters : health education, summarization of patient statements, talking on the patient's level, and clarifying one's own statements, addressing patient problems of daily living, social relations, and emotions and psychosocial counseling. Johnson et al.,³⁶ and Jones et al.,²⁸ demonstrated that verbal information and instructions are significantly less effective than written/printed information for the reason that patients and families quickly forget what is said to them. The vast majority of literature supports that information should not be only verbal but also supplemented with written information in the form of protocols or brochures, leaflets or instructions that achieve the maintenance of information over time. 4,19,28,36

Moreover, concerns are raised about information and the emotional state of patients. For instance, information should be discouraged in patients who experience anxiety or can not handle with detailed information. On the contrary, according to an earlier study by Lindsay et al.,³⁸ well informed patients in the waiting room just before surgery experience lower levels of anxiety. Similarly, according to Davies et al.,³⁹ high levels of satisfaction with the provided information were associated with lower scores on the Hospital Anxiety and Depression Scale.

Another equally important factor while providing information is assessing the way patients perceive the disease. Czar et al.,¹⁷ suggested that the efficiency of information depends on the way patients perceive the disease while Scott et al.,⁷ highlighted that the views of health professionals and patients about the disease are often quite different. Indeed, information based on patient needs as perceived by themselves, including their expectations, goals and feelings is more effective than information based only on the opinions of health professionals about what patients need to know about their health. To tailor information to meet individual needs, the needs have to be articulated by patients themselves. Unfortunately, Scott et al.,⁷ claimed that it is not really known whether provided information based on practitioners' perceptions is viewed by patients as important. Though current knowledge about patients' information needs is restricted to medical and nursing view, however it is widely accepted that the patient perspective of information should be taken into account routinely when assessing planning of care.

Another significant area related to information is involving family especially partners, who are often considered as important "caregivers". Indeed, they have different information needs that should be met separately. Interestingly, partners frequently feel distressed when they realize that they must assume responsibility for day-to-day care especially when the period of hospitalization is over. ⁴⁰⁻⁴⁴

Driscoll et al.,⁴⁴ demonstrated that carers received little information by health professionals concerning their patients' health problems and care at home. Furthermore, the carers' health and employment status were often not evaluated in their patients' discharge plan. Carers who were present when their patients received postdischarge information experienced a decrease in anxiety during their patients' convalescence at home, greater satisfaction by the provided information while their patients experienced fewer medical problems post-discharge.

Conclusions

Taken for granted that coronary artery disease is a major life-threatening event that can be extremely stressful, it is fully understandable that successful cardiac treatment and rehabilitation presupposes sufficient provision of information which enables patients to comply with the treatment regimen and make informed decisions about necessary life style changes.

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