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ISYDE-2008
Study presentation
The Italian SurveY on carDiac rEhabilitation: a snapshot of current cardiac rehabilitation programmes and provides in Italy

ISYDE 2008
Presentazione dello Studio
Il Survey 2008 sulla Cardiologia Riabilitativa Italiana: una istantanea delle strutture e dei programmi di Cardiologia Riabilitativa in Italia

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on behalf of the ISYDE 2008 Investigators of the Italian Society of Cardiac Rehabilitation and Prevention (GICR)

ABSTRACT: ***ISYDE-2008. Study presentation. The Italian SurveY on carDiac rEhabilitation: a snapshot of current cardiac rehabilitation programmes and provides in Italy. R. Tramarin, S. De Feo, M. Ambrosetti, R. Griffo, F. Maslowsky, P. Vaghi.***

The Italian Society of Cardiac Rehabilitation and Prevention (GICR) has developed the ISYDE-2008 survey with the purpose to take a detailed snapshot in terms of number, distribution, facilities, staffing levels, organization, and programme details of CR units in Italy and to compare actual provision with the recommendation of National GL for CR and secondary prevention.The study will be carried out with a web-based questionnaire running on the GICR website in 2 weeks from Jan. 28 to Feb. 10, 2008. The first part of the questionnaire is designed to collect information on the institutional organization of the CR unit, on its location and functional relationships within the hospital, on the number of beds for inpatient CR units and hours of activity for outpatient and home–based services, on the composition of the core and multidisciplinary teams, and finally on the components of CR programmes.In the second part of the survey, CR directors will be requested to report for each patient discharged during the 2 weeks of the study, indications for admission to CR, time of enrolment, comorbidity, complications, risk profile, diagnostic procedures, exercise and educational programme, discharge modalities, treatment at discharge and follow-up schedule.More than 2300 pts are expected to enter in the survey, whose results depicting the status of CR in Italy will be available within April 2008.

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Introduction

Comprehensive cardiac rehabilitation (CR) and secondary prevention programmes are recognized as a very effective approach for cardiovascular risk reduction and long-term care of cardiac patients as well as of subjects with multiple coronary risk factors. Available economic evaluations suggest that comprehensive CR is a cost-effective intervention following an acute coronary event and is economically justified. Secondary prevention, through CR programmes, is now recognized as integral to the comprehensive care of patients with cardiovascular disease. As a result, the more recent guidelines (American Heart Association e American College of Cardiology, European Society of Cardiology) [1-6] clearly indicate that CR should be integrated in the long-term care of all patients with coronary artery disease [3, 5, 7, 8] and chronic heart failure.

In the year 2006 the Italian National Program for Guideline (PNLG) published the guidelines on cardiac rehabilitation (CR) and secondary prevention, which were endorsed by the Italian Agency of Regional Health Systems (ASSR) [9]. Indeed, the implementation of guidelines and recommendations remains sub-optimal. Overall, cardiac rehabilitation is not a prominent item in public health expenditure. Although in developed countries over 80% of total days in hospital and 70% of current health spending (95% for old population) is due to treatment of chronic patients, there remains a gross imbalance between expenditure on chronic and acute patients. Evidently, a much higher proportion of health spending (public expenditure) is still allocated to the acute phase [10, 11]. Moreover, the exercise training alone is still considered as the primary component of the rehabilitation program. Furthermore a great variability exists in Italy in territorial distribution and provision of CR services.

Improving the funding and the profile of cardiac rehabilitation requires a change of attitude within both the primary care trusts and the cardiac professional community. With this purpose, since 1996 the Italian Society of Cardiac Rehabilitation and Prevention (GICR) promoted and carried out three detailed inventories of available cardiac rehabilitation programmes [12, 13]. In 2001 the first ISYDE project (Italian SurveY on carDiac rEhabilitation) offered a window on cardiac rehabilitation services, illustrating the core components of the existing programmes. At that time, the analysis highlighted some important discrepancies among different regions in Italy, with 57% of the CR units located in the North of the country (n. 144 in total) (fig. 1), 58% in public hospitals, 23% in private hospitals, 8% in rehabilitative hospital, and only 2% in university clinics. The majority of patients were admitted to CR units after cardiac surgery (55%); PTCA and chronic heart failure were respectively the 4 and the 9.6% of indications for admission to cardiac rehabilitation programmes (fig. 2). Most of Italian CR units showed a definite program for risk stratification and secondary prevention and in particular, the number of CR units was increased. Nevertheless, at that time there was still a lack of sufficient standardized procedures, together with the need for suitable indicators of quality of care of treatment.

The current survey, which is more comprehensive, aims to find whether or not progress has been made in cardiac rehabilitation practice. This update has the primary purpose to take a detailed snapshot in terms of number, distribution, facilities, staffing levels, organization, and programme details of CR Units in Italy and to assess current implementation of contemporary guidelines and recommendation of CR and secondary prevention.

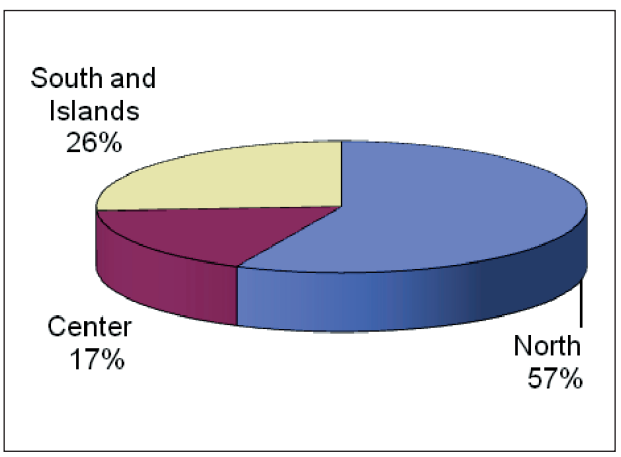


Figure 1. - Distribution of Cardiac Rehabilitation Centres in Italy, 2001.

Methods

Participating Centres

The ISYDE-2008 is designed as a multicenter, longitudinal, prospective study, with the primary purpose of identifying all rehabilitation centres existing in Italy in 2008. The second purpose is to describe the population referred for cardiac rehabilitation programmes and the comprehensive and detailed components of the programme offered.

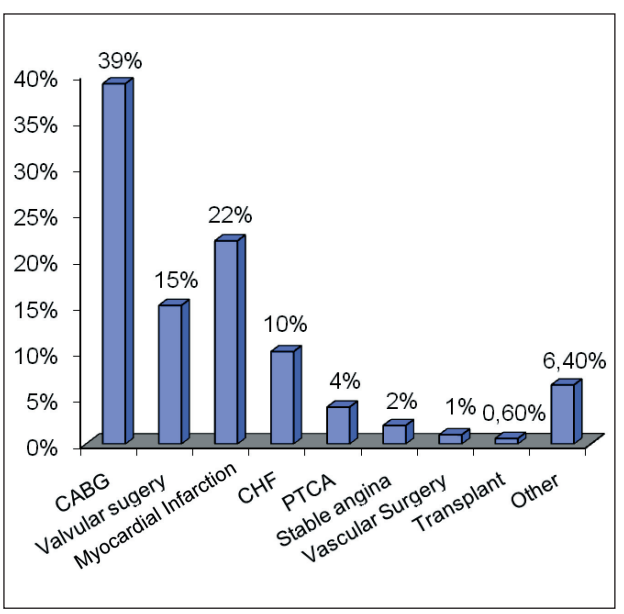


Figure 2. - Clinical characteristics of patients admitted in CR units in Italy, 2001.

The survey is aimed to be carried out in all cardiac rehabilitation centres either residential or ambulatory (throughout Italy) that agreed to take part in the survey. Medical centres are invited to participate in the survey on a purely voluntary basis, by the regional GICR coordinator, responsible for maintaining contact with the investigators in each of the participating centres, and for overseeing the implementation of the survey protocol. In addition to the recruitment efforts of the regional coordinators, information about the survey is posted on the GICR website www.gicr.it, inviting all interested investigators to join.

All 144 Cardiac Rehabilitation units of the 2004 inventory are invited to join the survey. Every regional coordinators of the GICR will moreover update the list of all Italian CR Units, in order to indicate new Centres.

Objectives of the study

The first part of the questionnaire is designed to collect information on the institutional organization of the CR unit, on its location and functional relationships within the hospital, on the number of beds for inpatient CR units and hours of activity for outpatient and home–based or tele-care services, on the composition of the core and multidisciplinary teams and on the description of the professional background of the members, on the types and components of CR programmes. At the end of this activity, a complete list of the Rehabilitation Centres in Italy will be available in the web site of the GICR www.gicr.it. The list is provided with contact data (staff, correspondence address and telephone, e-mail), CR services and facilities.

In the second part of the survey data on indications for CR, clinical characteristics of patients referred, risk profile, diagnostic procedures performed, exercise and educational programme, treatment and the follow-up will be collected.

Study design and procedures

The enrolment period will last 2 weeks. Participating centres are asked to recruit all consecutive patients discharged from rehabilitation program between the 28th January and the 10th February 2008. An ID and login password for restricted access to questionnaire and survey forms will be provided to the site referent of participating centres.

Web based electronic case report forms will be used for data entry and transferred via the web to a central database (table 1).

The data collection instrument is designed according to a multiple choice style, with jump menus or select boxes in order to reduce the risk of confounding answers (figure 3).

Each participating centre is asked to provide a description of the medical centre. The questionnaire sought information on team members, protocols, funding. Participants will be asked to complete this part of the CRF from the first day of the survey (the 28th of January).

In the second part, data on patients accessing the service, programme content, methods of recording patients' details and arrangements for follow-up are collected.

Questionnaires are designed to gain information to collect quantitative data of the key personnel providing cardiac rehabilitation services, examining in detail the content of all phases of the cardiac rehabilitation programme.

Patient identification is not recorded on the case report forms.

Table 1. - Components of the survey

Characteristics of the Rehabilitation Centres in Italy participating to the survey	Characteristics of patients discharged from rehabilitation programmes between the 28th January and the 10th February 2008
1. Contact data of the CR centre: staff, correspondence address and telephone, e-mail	7. Age
2. Location and functional relationships within the hospital	8. Sex
3. Feature of the Cardiac Rehabilitation unit (number of beds for inpatient, hours of activity)	9. Indication to cardiac rehabilitation programme
4. Institutional organization of the Cardiac Rehabilitation Units (resident, outpatient and home-based or tele-care services)	10. Acute-phase-complications
5. Core components of the CR programme	11. Rehabilitation-complications
6. Composition of the multidisciplinary team and the description of the professional background of the members.	12. Co-morbidities
	13. Risk profile
	14. Diagnostic procedures performed
	15. Educational programme
	16. Psychological programme
	17. Length of programme
	18. Discharge modalities
	19. Treatment at discharge
	20. Follow-up schedule
	21. 12-months follow-up: major cardiac events, major medical expenses (hospitalizations, ER accesses), adherence to pharmacological and non-pharmacological prescriptions in secondary prevention, risk profile improvement

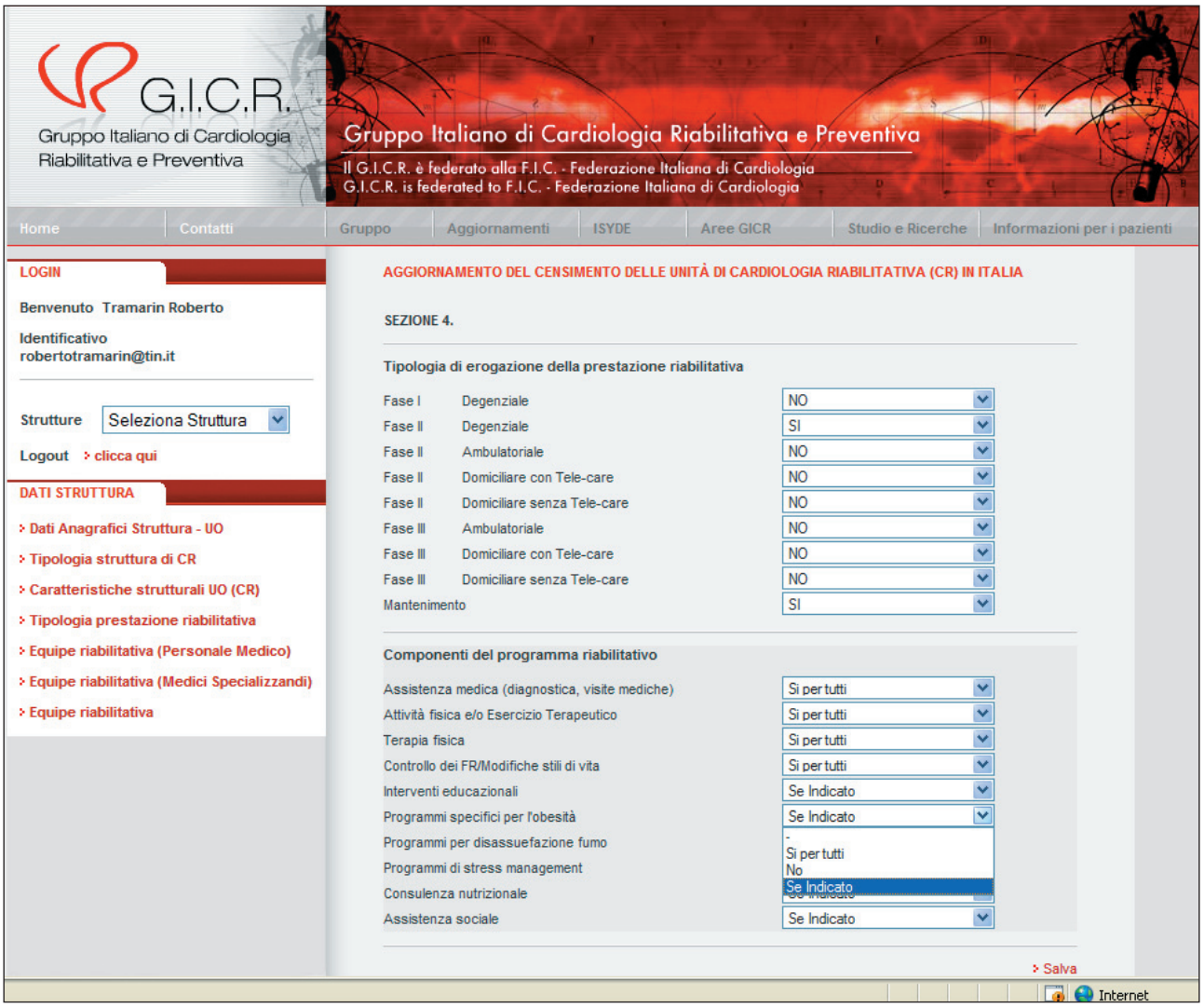


Figure 3. - Example of on-line web-based data collection. In order to reduce the risk of confounding answers, the e-forms of the questionnaire and CRF are designed according to a multiple choice style, with jump menus or select boxes.

In addition to data regarding the pre-hospital and in-hospital course, patients' follow-up data will be collected at 12 months.

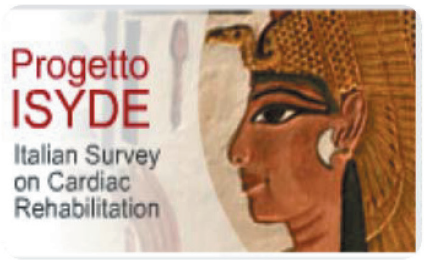
Chronology

1. December 2008: the GICR regional Coordinators update the list of all Italian CR units.
2. January 2008: a standard letter will be posted to all CR units. A reference person for each unit is contacted and informed of the initiative, in order to elicit their participation. A formal presentation of the survey will be sent to the hospital direction of each centre.
3. From the 15th January 2008: The ID and login password for the questionnaire access will be send to the reference person of each CR centre.
4. The 28th January 2008: starting of the survey.
5. The 11th February 2008: end of the survey. Last day for compilation of the first part of the questionnaire (characteristics of the Rehabilitation Centre: Table 1, items 1-6).
6. The 18th February 2008: last day for the compilation of the patients characteristics questionnaire (Table 1, items 7-21).
7. From the 18th to the 29th February 2008: entry-data check by the GICR regional Coordinators.
8. March 2008: a complete list of the CR centres in Italy will be available in the web site of the GICR www.gicr.it or www.gicr.eu. Only centres that have agreed to participate on the survey will be included in the updated inventory and will be published.
9. June 2008: the results of the survey will be published.
10. The results of the ISYDE-2008 survey will be presented at the GICR National conference (Ostuni, BR, October 2008).

Discussion

The ISYDE-2008 is a voluntary, national program designed to provide specific information in regard to the institutional organization and the core components of cardiac rehabilitation in Italy.

The ISYDE 2008 will be a pragmatic survey, with broad participation throughout Italy to present the real rehabilitation world and clinical profile of patient referred to these programmes. For such reason, the survey is designed to be conducted in all



ISYDE 2008

28 Gen. – 10 Feb. 2008

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SAVE THE DATE

28 GENNAIO 2008

FOTOGRAFIAMO INSIEME LA CARDIOLOGIA RIABILITATIVA IN ITALIA

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Presentazione del censimento e della survey.

a. Razionale
b. Obiettivi
c. Raccolta dati e data-base
d. Cronoprogramma

PER INFORMAZIONI

Delegati Regionali GICR: i contatti sono riportati nella sezione Delegati Regionali del sito
E-mail: isyde@gicr.it
E-mail: segreteria@gicr.it

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cardiac rehabilitation centres present in Italy at the beginning of the year 2008 without any selection criteria. A great effort is in fact made in the updating of a complete list of Centres.

More than 2300 pts are expected to enter in the survey; all consecutive patients discharged from the Rehabilitation units in the two weeks period are eligible; there are no exclusion criteria. The dimension of surveyed population (approximately 5% of patient admitted in 2008 to CR units) is expected to be high representative of cardiac patients attending rehabilitation programmes. Moreover, each patients considered in the survey will be followed-up for 12 months after discharge. Each Centre is responsible for gathering complete information.

Data collection follows standardized criteria. A questionnaire was developed with standardized variables and data are entered on-line on a protected web-site. The website is an essential method for disseminating results.

Surveys and registries are an effective means of assessing the implementation of guidelines. It is recognized that although the adherence to guidelines has been shown to be associated with improved outcomes, their implementation remains sub-optimal. It must be underlined that systematic monitoring of current situation should also assist health care providers and policy makers and consumers in the organization of comprehensive programmes that must be delivered to the large constituency of patients now considered eligible for CR.

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