Survey of health and social-health services for people with dementia: methodology of the Italian national project

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Abstract

People with dementia have special assistance needs. Worldwide problem is to ensure access to quality health services. Our study supported by the Italian Ministry of Health reports methodology features of a large survey project conducted to identify and to collect information on health and social health services for people with dementia in Italy. Among all Italian regions, about two thousand services available to individuals with dementia disease and their caregivers were identified. These services included memory clinics, daycare centers and residential care facilities, totally or partially covered by the public healthcare service. A survey questionnaire was designed to collect information and a web-platform system was developed to manage data from all services. Of great importance, the web-platform is capable to display surveyed services as an on-line map regularly updated and easily accessible from the Dementia Observatory website (www.iss.it/demenza).

BACKGROUND

Among chronic diseases, dementia and cognitive impairments are, by far, the most important contributors to disability, dependence, and account for transition into residential and nursing home care in high income countries [1].

People with dementia have special needs for care. The 2012 World Health Organization Report evidenced that dementia care should be promoted as "top priority" for National public health agendas [2].

Getting the necessary support and care depends on several factors. Availability, accessibility and readiness are key elements of the complex health and care systems involved both in the diagnosis and care of people with dementia [3].

The Word Health Organization considers availability and readiness the two main aspects of service quality. Service availability refers to the physical presence or capability to reach out facilities; service readiness refers to the ability of health facilities to provide a range of offer, including presence of trained staff, guidelines, infra-structure, equipment, medicines and diagnostic tests. Service availability and readiness are prerequisites to quality services but do not guarantee delivery of quality services [4].

At national level several studies have been conducted to survey and to collect information on the resources, distribution and practices adopted by services for people with dementia [1, 5-12]. These studies focus on the activity of memory clinics, semi-residential social-health structures and residential care facilities but do not report monitoring systems to update and to implement information of services' activities over time. Lack of information in updated data collection limits the capability to ensure indicators of quality services. Also, it is not possible to compare services' organization among countries or to compare services organization based on geographic distribution or types of services within the same country [3, 4].

To the best of our knowledge, only two studies, one conducted in France and the other in England, report implementation of monitoring systems for services' ac-

tivities for dementia. However, both studies focus on the experience of memory clinics/units only.

In France, Measure 34 of "The French National Plan for "Alzheimer and related disorders 2008-2012" entitled "Setting up epidemiological surveillance and follow up" aimed to provide epidemiological data and activity indicators of the specialized centers for each region with the introduction of a National database (known as the "BNA" the National Alzheimer data Bank). The BNA comprises a centralized information system to collect data from participating centers, and a data management system to ensure reliability of the information collected with a limited data set defined by National consensus. This measure was implemented to provide a nationwide system to collect activity data, to ensure epidemiological surveillance and follow-up within specialized centers (memory units, centers and independent specialists) [13].

In England, the "2009 English National Dementia Strategy" recommended the creation of memory clinics/services defined as a multidisciplinary team (either National Health System, NHS, or private) to assess, diagnose dementia, and provide psychosocial interventions for dementia [7]. In 2012, the Royal College of Psychiatrists, as requested by the English Department of Health, constructed the Memory Services Register reporting data on 214 memory clinics [14].

In 2000, the Italian Ministry of Health and the Italian National Institute of Health (*Istituto Superiore di Sanità*) implemented the Cronos study. Main objectives were to characterize the population of patients with Alzheimer's disease treated with acetylcholinesterase inhibitors; to monitor effectiveness and drug safety; to identify variables that may predict response to therapy; and to inform physicians and caregivers about the correct use of drugs [11]. Among all Italian regions, about 500 memory clinics, named Alzheimer's Evaluation Units (AEU, *Unità Valutative Alzheimer*), were identified to coordinate the complex process of caring for individuals with conditions leading to dementia [5, 6, 11, 15]. These centers were specifically dedicated to the diagnosis and management of Alzheimer Disease and other dementias. In 2002 and in 2006, two surveys were conducted to census and to characterize the AEU activity, assessing the important role of AEU services in the diagnosis and treatment of people with dementia, with wide variations at regional and local level [5, 6].

Italy is divided in 18 administrative regions and 2 autonomous provinces. The Italian NHS is structured at national, regional, and local level. Regions have substantial autonomy in determining the macro structure of their local health systems. At local level, health units are led by a general manager appointed by the governor of the region. Local health units are organized in a network of public health care and social care including deliver primary care, hospital care, outpatient specialists. Over time, this type of organization has led to a broad regional variability and to some inequalities in terms of available resources and services, including those for patients with dementia, resulting in a lack of national standards [16].

Currently, in the Italian NHS, management and care of people with dementia (i.e. diagnosis, assistance, rehabilitation) are under direct responsibilities of different health and social health services. Information on their features (i.e. number, distribution, activity) are not always available.

Although at regional and national level lists of health facilities exist, there are no lists of dementia health facilities (master list) [4].

The first "Italian National Dementia Plan" was formulated in October 2014 by the Italian Ministry of Health in collaboration with the health and social sectors of all regions, the Italian National Institute of Health and the three major national associations of patients and caregivers [17, 18]. Among other actions, the DNP renamed the existing memory clinics, UVAs as "Centers for Cognitive Disorders and Dementias" (CCDD) (named *Centri per i Disturbi Cognitivi e le Demenze*), maintaining their central role in the network of health care and social care services and recognizing the need to reorganize the dementia services in integrated care pathways.

Related to the development of the "Italian National Dementia Plan", the Italian National Institute of Health was assigned to manage a national project entitled "Survey of the social and health services dedicated to dementias and creation of a specific website: Observatory for dementias" supported by grants from the Italian Ministry of Health – National Center for Disease Prevention and Control (the 2013 programs of research actions – central actions).

Our study reports the methodology procedures used to conduct the web-based survey. This web-based survey was designed to census and collect information on all health and social health services for individuals with dementia. Specifically, the methodology enabled us:

- to census both public and accredited with the NHS available services, including memory clinics, daycare centers and residential care facilities;
- to collect information on available services that deliver health-care interventions for people with dementia and their caregivers within the structure, process and outcome indicators framework;
- to develop a web-based platform to collect, to update data of surveyed services and to organize the public list of available services for people with dementia as a dynamic online map;
- to implement and update the list in real time, and to easily access it from the Dementia Observatory website (www.iss.it/demenza).

METHODS
Action research theoretical framework

The survey was conducted under the action research theoretical framework. This is an overarching approach to research to be used when different phases – theoretical, empirical and operational – are closely connected and if the work of the researcher is contaminated with the action of the subjects studied. Action research is useful when applied to health services research [22], and met some features present in the survey of services for dementia. Action research is used in real situations, rather than in contrived, experimental studies, since its primary focus

is on solving real problems, and research is conducted in unique health and social health services [22, 23]. In the action research, activity proceeded on an iterative cycle, considering what the problem is, proposing action to resolve the problem, tacking action, learning lessons from the results of the action, reconsidering what the problem is and back to and through the cycle [22].

The structure, process, outcome framework

We used the conceptual framework of Avedis Donabedian which is widely applied for evaluating the quality of health services [24-27]. Accordingly, three dimensions were used to describe, analyze and evaluate the quality of care: (1) structure, (2) process, and (3) outcome. "Structures" refers to material resources such as facilities, equipment, financing, human resources (i.e. number and qualifications of personnel, organizational structure including medical staff, organization and methods of reimbursement). "Process" denotes what is done in giving and receiving care, i.e. practitioner's activities in making diagnosis, recommending or implementing treatment, or other interactions with the patient. "Outcome" measures attempt to describe effects of care on the health status of the patients and of the populations [27].

Given the absence of National standards in the area of dementia services, the structure/process/outcome dimensions were used as a guide to formulate the core structured questions of the survey questionnaire, to collect information on each of these areas, and to develop National indicators for dementia facilities.

Survey research approach

A survey research approach was used to conduct the study [19-21]. First, we created a standardized questionnaire form to provide a snapshot of all active services rather than to collect data on a sample of services. Then, we created an open cohort of surveyed services to collect data at multiple time points.

Target and survey facilities (eligible services)

The survey was first developed to census available services assisting individuals living with dementia.

In our study, we identified and included three types of services of health and social health structures totally or partially covered by the public healthcare service:

1) memory clinics (MCs), previously named UVAs and currently renamed "Centers for Cognitive Disorders and Dementias" (CCDD). These centers are funded by the NHS and entrusted with the prescription of specific drugs for Alzheimer Disease (donepezil, rivastigmine, galantamine, memantine) on the basis of the diagnosis and treatment plan [28, 29]. They are in charge of assessment, diagnosis and management of people with cognitive disorders and dementia including services/outpatient clinics, located in different structures but functionally connected with a principal CCDDs (commonly named sub-UVAs);

2) daycare centers/Integrated daycare centers (DCs) (named *Centri diurni*). They are semi-residential social-health structures, licensed, registered, listed, certified or otherwise regulated by the Regional NHS, and are

either partially or completely funded by the NHS. DCs were surveyed only if working with individuals with dementia, with or without dementia special care units;

3) residential care facilities (RCFs) (named *Strutture residenziali*). They are healthcare and social-health residential structures, licensed, registered, listed, certified or otherwise regulated by the Regional NHS, and are either partially or completely funded by the NHS. RCFs were included if working with individuals living with dementia, with or without dementia special care units.

We did not include private facilities for not being partially or completely funded by the NHS, and social structures unable to assist people with diseases of high medical relevance. Structures licensed to serve only mentally ill or developmentally disabled patients were also excluded.

As no master facility list was available for dementia service, we first identified and contacted dementia representatives of all Italian regions administrations demanding the list of regional facilities. If services were not identified through representatives, regional websites were consulted for contact information.

The survey resulted in a preliminary list that included about 2000 services named "surveyed facilities". The surveyed facilities were memory clinics, daycare centers and residential care facilities either totally or partially covered by the public healthcare service. Distribution of the identified/mapped services by type and region is shown in *Table 1*.

Data collection instrument

Survey questionnaire

A specific questionnaire for each type of service was developed to collect data in a standardized form.

A group of researchers, including specialists in the dementia field, epidemiologists, and members of target services, participated in the development of the survey questionnaires and ensured validity of the questions included (content validity).

The survey questionnaires consisted of five parts and comprises a set of core questions to assess the current status of clinical, non-residential and long term care facilities. Questions were specifically formulated to collect information on:
- location and contact information;
- operating hours and days;
- personnel (i.e. staff profile and composition), waiting time for first assessment, procedures and service documentation;
- provided treatment and services;
- specialized activities and data on patient numbers.

To verify that CDs and RSs services met eligibility criteria, specific questions on whether or not the centers were private or public and had in charge individuals with dementia were included in the questionnaire.

Domain and topics in the core component of the survey questionnaire are summarized in *Table 2*.

The survey questionnaire was self-administered, computer assisted and filled in by the clinical representatives of the services. Both closed questions with pre-coded response options, and open questions to collect not pre-coded or not provided answers were included.

Table 1
Distribution of the services included in the preliminary list of dementia survey facilities by type and Italian region

Italian Regions	Number of CCDDs	Number of day care services	Number of residential facilities
Lombardia	71	307	139
Emilia Romagna	64	21	16*
Piemonte	36	18	28
Veneto	43	94	16
Liguria	24	17	17
Prov. Aut. Bolzano	4	13	54
Prov. Aut. Trento	7	2	54
Friuli-Venezia Giulia	15	34	121
Valle D'Aosta	4	0	3
Toscana	24	37	74
Lazio	35	19	111
Marche	15	9	32
Umbria	31	12	57
Calabria	35	0	0
Campania	84	7	23
Puglia	31	18	*Not detected*
Sicilia	36	18	52
Sardegna	11	6	18
Abruzzo	11	5	16
Basilicata	3	3	1
Molise	3	1	1
Geographical region			
North Italy	268	506	448
Central Italy	105	77	274
Southern Italy and Islands	214	58	111
Italy	587	641	833

CCDDs: Centers for Cognitive Disorders and Dementias
*Only Alzheimer special care units are included
Note: 0: No center available

Table 2
Section/Domain and topics included in the core component of the survey questionnaire of dementia service

Section/ Domain	Topics
Location and registry service	Detailed information on location, name, phone number and address of the services; types of services; type of funding and methods of reimbursement Number of licensed, registered, or certified residential care beds/places (*only for day care and residential facilities*)
Access to the service	Operating days and hours per week (*only for CCDDs and day care facilities*) Modality to access the service (e.g. telephone number to book; wording for medical prescription*)
Organizational aspects of the services	Staff profile and composition Waiting time to access the service Procedures and service documentation (*Availability of structured procedures for data collection of the activity; Availability of a document on integrated care pathway *)
Treatments and services provision	Services provided (*i.e. Pharmacological and non-pharmacological interventions; Non-pharmacological interventions provided to caregivers *) Access to other health professionals and care coordination Neuropsychological tools used to confirm the dementia diagnosis*
Data on activities and patient numbers	Number of patients with and without dementia diagnosis in the last year Patients assessed per month* Patients assessed for the first time per month* Number of patients in charge visited annually (at least one time per year)* Average of daily patients; percentage bed occupancy, turnover interval rates (*in day care facilities/services facilities*)

*CCDDs: Centers for Cognitive Disorders and Dementias
Note: The full survey questionnaire is available in Italian upon request

Open questions were also used to collect specific information for each service and answers useful for the topic. The majority of questions were mandatory. Responders needed to enter a response to move forward. Some questions were also an automatic check of data already entered to avoid inconsistent answers.

Wording and graphic form of the questions have been carefully chosen to make the questionnaire clear and easy to be completed [30].

Cover letter

All participants were invited to participate to the survey by email [19]. An introductory cover letter explained aims of the survey, that the survey was conducted by the Italian NIH and response was mandatory as per the Ministry of Health's request. Cover letter included a link to access the online questionnaire. Contact name and address of the principal investigator, details of how and why the respondent was selected, and any potential benefits or harm resulting from the study were also provided.

Pre-test

Questionnaires were pre-tested on a pilot sample of three members of target services (one representative for each typology of services) to ensure that questions and instructions were clear and had uniform meaning to all participants. As no critical issues were found during pre-test, the questionnaire was considered final.

The Dementia Observatory web-platform system for data collection

A web-platform system was developed to manage the large amount of data from a very high number of services:

- at back office level, a web-based data entry system allowed to collect and to update data of surveyed services: each service facility was assigned with a unique code. Once authorized, each center was able to fill in the questionnaire in a web-based data entry system. Data were entered in an open data modality and enabled to be checked and/or update;
- at front office level, the platform allowed to organize and publish the validated and/or officially confirmed list of available services as a dynamic online map easily accessible from the Dementia Observatory website (www.iss.it/demenza).

Dementia survey facilities list: update and validation

Starting from a preliminary list, number and accuracy of services were improved and updated. We also verified compliance with inclusion criteria/characteristics and excluded ineligible services. The preliminary list of services was considered as upgradable to include services not initially identified.

Before being included in the data analysis and published in the online map, the updated list of dementia survey facilities was validated and/or officially confirmed by the regional representatives or the regional health department.

Once included in the on-line map, the list of services is implemented and updated in real-time through the web-based data entry system. Information contacts are regularly downloaded to generate updated mailing lists.

DATA COLLECTION AND PROCESSING ANALYSIS

In December 2014, survey questionnaires were first mailed to the preliminary list including about 2000 survey facilities (*Table 1*).

The Dementia Observatory web-platform system allowed creation and management of databases including data storage and retrieval. Data collected through the web-platform system were then exported in different formats for statistical data analysis (SPSS ver. 20, IBM, USA). Null responses generated by typing errors or "impossible" responses to survey questions (i.e. to the question "how many days is the unit open?": outliers were considered numbers equal and/or lower than zero or higher than 7) were removed from calculations if not corrected within a given timeline.

To improve and maximize the number and accuracy of the survey response we used different strategies such as:
- participants were contacted by initial and follow-up emails and offered telephone support;
- undeliverable contact and/or incorrect e-mail addresses were checked and corrected;
- when requested, respondents were assisted to complete the survey;
- responders who could not initially participate and did not refuse were successively contacted.

The response rate of emailed services was used to describe the success of the survey and as a primary measure of survey's quality [19]. In our study, the initial list of memory clinics, daycare centers and residential care facilities was used to improve the response rate to the survey.

Some components of weighted response rate calculation were also considered:
- eligible responding (completed questionnaire, respondent confirmed to be eligible for survey participation);
- ineligibles (no active services, private facilities, services not assisting people with dementia);
- eligible non-responding (questionnaire not completed with sufficient information to indicate that the service was eligible);
- unknown eligibility (non-contacts and/or refusals with insufficient information to determine eligibility).

Based on the survey questionnaire structure, process and outcome dimensions were used to describe and to assess aspects of dementia facilities and to elaborate proposal of indicators that are under development (*Table 3*). Data collected through the online platform for each type of service are under review and will be reported in upcoming publications.

Table 3

Examples of proposal structure/process/outcome indicators based on the questionnaire used to collect information on dementia facilities

Typology	Indicator
Structure	Number and qualifications of personnel (*i.e. Proportion of neurologist to other doctors in the CCDDs; Medical staff*)
	Types of services provided
	Availability of structured procedures for data collection of the activity
	Availability of a document on integrated care pathway *
	Methods of reimbursement (*only for day care and residential facilities*)
	Operating days (and hours) per week (*only for CCDDs and day care facilities*)
	Waiting time to access the service (*expressed as average per admission*)
	Number of licensed, registered, or certified residential care beds/places (*only for day care and residential facilities*)
Processes	Number of patients in charge annually visited (assessed at least one time per year)*
	Average time spent per patient at first visit and controls*
	Neuropsychological tools used for dementia diagnosis formulation*
Outcome	Average of patients assessed per month*
	Average of patients assessed for the first time per month*
	Percentage of individuals visiting a CCDDs that received neuropsychological tools for dementia diagnosis formulation - *in the last year* *
	Percentage of patients with dementia and carers (expressed as average number of patients and carers) that received non pharmacological support after dementia diagnosis *in the last year**
	Percentage of patients with dementia (expressed as average) that received an antipsychotics prescription *in the last year**
	Average of daily use; percentage bed occupancy, turnover interval rates (*in day care facilities/services facilities*)

*Only for CCDDs, Centers for Cognitive Disorders and Dementias

DISCUSSION AND CONCLUSIONS

In Italy, more than 1 million individuals have dementia and more than 3 million individuals directly or indirectly are involved in their assistance. As in other developed countries, these numbers are expected to significantly increase in the future.

To the best of our knowledge, this is the first study reporting a mapping system to gather and gain information on the range of care and services available to individuals with dementia disease and caregivers [31].

It is imperative to estimate availability, utilization, and providers of dementia services at country level. Indeed, improving quality of care is a high priority in all countries.

Survey of services for people with dementia was and is still part of the health care program of the Italian National Dementia Plan [17, 18].

The two previous Italian surveys only focused on CCDDs [5, 6]. For the first time, our manuscript reports a survey that includes all type of dementia services available in Italy and maps services in structured/systematic manner including the different situations co-existing at regional and national level.

In developing this mapping system, we used as theoretical framework the action research principles. During this research many difficulties needed to be addressed and changes to be applied quickly or holistically. This required flexible planning and, in accordance with the action research framework iterative cycle tenets. In this contest, the first step has been to assess facility availability to determine types of care, services, and providers of services for people with dementia. Then the list of services was included in the on-line map and made easily accessible from the Dementia Observatory website (www.iss.it/demenza). The list was therefore implemented and updated over time and in-real-time to track and storage precise information of all surveyed services.

The survey showed discrepancies in availability of dementia services among regions. Our analysis indicated that access to health care may be restricted not only because of financial reasons, but also because of geographic barriers, waiting times and other reasons.

The development of indicator measurement and monitoring allow to document the quality of care, to make comparisons (benchmarking) over time between places (e.g. Residential care services), to set priorities, to support accountability, regulation, and accreditation and to support quality improvement and patient choice of providers.

Results from these survey will provide fundamental information to further guide health systems planning including planning of resources available within geographic areas and the proximity of essential health services to higher levels of care.

Our web-based survey methodology has huge potentials and implications because it allows to continuously and in real-time manner update data collection and information from/to all levels of assistance. More importantly, the capability of our database to create an updated and immediate snapshot of services represents a fundamental resource to citizens to access available facilities and to professionals to establish collaborative networks among facilities.

Conflict of interest statement

There are no competing interests to declare.

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