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A Short Version of SIS (Support Intensity Scale): The Utility of the Application of Artificial Adaptive Systems

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The aim of this paper is to present a shortened version of the SIS (support intensity scale) obtained by the application of mathematical models and instruments, adopting special algorithms based on the most recent developments in artificial adaptive systems. All the variables of SIS applied to 1,052 subjects with ID (intellectual disabilities) involved in the validation of the Italian version of SIS, were analyzed with the aforementioned artificial adaptive systems. This study has identified 56 items, whose responses are able to explain up to 89% of sample variance. Secondly, these same variables have been analyzed by means of specific semantic networks, in order to demonstrate the plenty of scientific suggestions emerging from such an approach to statistic processing.

Keywords: neural network, QoL (quality of life), intellectual disability, individual planning

Introduction

Concerning the operational application of QoL (quality of life) construct, also in Italy, the SIS (support intensity scale) has been introduced since 2007, after its own original publication in USA (2004). SIS has been originally conceptualized and formalized in the US (Thompson et al., 2004), has already used in some European countries, and it is now available in an Italian standardized version. SIS is an important instrument to collect data about the needs of support and to plan adequate supports for people with ID (intellectual disabilities) in order to achieve a better QoL. It permits to plot an individualized support need profile of a person with ID. On the basis of the collected data, an operator of the staff is able to measure quality and quantity of the help needed for a person to perform everyday life activity with efficacy and dignity. Each item of the scale must be measured in

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terms of frequency, intensity and typology of the support needed in different areas of human activities linked with QoL domains. More precisely, the need of support, which is not a generic human need, is calculated throughout the various daily life activities aligned to the corresponding personal QoL domains. The support need profile is a source of indications about the resources needed to support people with ID and is a strong suggestion to determine the care and intervention charge of the same people (ANFFAS (National Association of Families of People with Intellectual and Relational Disabilities), 2007). SIS is composed of six subscales, each of which explores and provides information in specific areas of support needs, such as home living, community living, life learning activities, occupancy, health and security, and social activities. Added to this section, there is another section devoted to protection and advocacy needs of support assessment. A third section is devoted to the assessment of support needs concerning medical and behavioural non-ordinary support needs.

With such an instrument, it is possible to obtain a measure of a variable system which is different and complementary to adaptive behaviours.

There is no kind of interview at the moment, that produces such extensive and systematic information as the SIS does. The SIS profile underlines and points out exactly the specific needs of support and indicates when, how often and which kind of support is needed by the person in order to get a better standard of QoL. It is important to discriminate between the concept of “need” and the concept of “need of support”: SIS is not oriented to identify what people generally want, or perceive as a lack of something or a drive towards a satisfaction, but what they do practically need to bridge human functioning and standard QoL.

The AAIDD (American Association of Intellectual and Developmental Disabilities) model and its SIS evolution seem to facilitate the operational integration of a comprehensive bio-psycho-social approach to ID. Furthermore, according to the 10th edition of the AAIDD Definition Manual, SIS and ICF (International Classification of Functioning, Disability and Health, World Health Organization, 2001) together may be usefully integrated in research and practice at organizational and administrative levels also to determine service budgeting and granting. Particularly, SIS proved to be an efficient tool and a reliable method for individual assessing and planning and a valid indicator to evaluate the factors involved in resource allocation (ANFFAS, 2007).

The Italian version has been validated in 2007, with a normative sample of 1,052 subjects with ID. The composition of standard sample is reported in Table 1. A complete data analysis with all the psychometrical characteristics, is reported on the manual of the Italian version of SIS (Cottini, Fedeli, Leoni, & Croce, 2008).

The application of the classical statistical techniques (e.g., the principal or independent component analyses) on variables in living systems of the real world, such as those obtained by SIS, has several limitations because of their non-linear distributions with contiguity as the only known element, giving origin to a “static” projection of possible associations among the variables. In order to reveal the intrinsic dynamics due to active interactions of these variables, analyses should be done by means of artificial adaptive systems (Buscema, 2008a; 2008b). These innovative algorithms, though applied with success in the field of biology (Penco, Buscema, Patrosso, Marocchi, & Grossi, 2008) and medical imaging (Buscema, 2008a, 2008b; Buscema, Catzola, & Grossi, 2008), are still rare in medical clinics (Grossi & Buscema, 2006; Grossi, Mancini, & Buscema, 2007; Buscema, Grossi, Intraligi, Garbagna, Andriulli, & Breda, 2005), such as the field of intellectual disabilities (Frimmel, Nappi, & Yoshida, 2004; Lee, Kim, & Jung, 2006).

The aim of this paper consists of presenting an abbreviated version of SIS, obtained through the application of special artificial adaptive systems. Such a short version of the scale should allow identifying

which variables, in different environments, are more relevant for a better individual support planning.

Methods and Materials

Subjects

Table 1 summarizes the descriptive statistics of the 1,052 subject standard sample. Its composition is substantially balanced for gender, 591 male (56%) and 461 female (44%), while the average age of the sample is 42.3 years (Standard deviation = 14.2) with a range between 16 and 81 years.

Instruments

SIS is a multidimensional instrument directed to assess the needs of support necessary to assure a standard QoL to people with ID. In the adult version (above the age of 16), it is composed of three sections. For the first two sections, each of the activities indicated by the correspondent item is investigated with a unipolar scale ranging from a score of 0 to 4 points, with some exceptions for specific items where the entire range is not applicable. Each item is measured in three different variables: frequency, daily time and type of support needed to perform at its best considered activity. It measures the increase of the amount of support needed, for example, if the type of support is evaluated, the score ranges from 0 (no support needed) to 4 (total physical assistance is needed).

Table 1

Composition of the Study Sample, Adapted From Cottini et al. (2008)

Age intervals	Number of subjects	Percentage (%)
16-19	50	5
20-29	158	15
30-39	246	23
40-49	273	26
50-59	189	18
60-69	106	10
70 and over	30	3
Sex	Number of subjects	Percentage (%)
Male	591	56
Female	461	44
Levels of ID	Number of subjects	Percentage (%)
Mild	164	16
Moderate	331	32
Severe	345	33
Profound	212	20
Residential setting	Number of subjects	Percentage (%)
Family	471	48
Group homes	130	12
Institutions	380	39
Missing data	71	1

All the standard scores obtained from all the components (under sections) of section one, provide a profile of support needed by that person and a composite SIS index, derived on the basis of each of the six SIS under section. Such a composite SIS index indicates globally the intensity of support needed for the same person.

The second SIS section named “advocacy and protection scale”, evaluates measures of self-protection needs

of support, while section three is composed of the “non-ordinary medical support needs” and the “non-ordinary behavioural support needs”. This section is devoted to assess which amount of intervention is necessary to cope with extraordinary medical and behavioural problems, as is reported in each specific item of the scales. All the details of standardization procedure are described in Cottini, Fedeli, Leoni, and Croce (2008).

Statistical Analysis

The whole collected data set has been examined in terms of outcomes: The total support need indexes have been shared out in three general classes, respectively 0-33%; 33%-66%; 66%-100% percentile referred to the standard sample. Then the results have been analyzed by the adaptive system, called TWIST (training with input selection and testing), through all the considered variables, including the social-registry ones, in order to understand and verify which are the most significant to represent the variance of a study sample (Grossi, Marmo, Intraligi, & Buscema, 2008).

The TWIST system consists in an ensemble of two previously systems: T & T (training and testing) and IS (input selection). The T & T system (Grossi, Mancini, & Buscema, 2007) is a robust data re-sampling technique that is able to arrange the source sample into sub-samples that all possess a similar probability density function. In this way, the data is split into two or more sub-samples in order to train, test and validate the ANN (artificial neural Network) models more effectively. The IS (Buscema, 2001-2002) system is an evolutionary wrapper system which is able to reduce the amount of data while conserving the largest amount of information available in the dataset. The combined action of these two systems allows for solving two frequent problems in managing ANN. Both systems are based on a genetic algorithm, the GenD (genetic doping algorithm) developed at Semeion Research Centre (Buscema, 2004).

For all these three systems (T & T, IS and TWIST), a special software designed by Semeion Research Centre was used (Buscema, 2002-2009; 2001-2002; 2006-2007).

After this processing, the features that were most significant for the classification were selected, and at the same time, the training set and the testing set were created with a function of probability distribution similar to the one that provided the best results in the classification. A supervised multi-layer perceptron, with four hidden units, was then used for the classification task (Buscema, 2004).

In the second phase, the significant variables have been further investigated by a new algorithm, neural networks based, able to optimize the associations of the whole dataset variables simultaneously, up to the third order. The name of the system is AutoCM (auto contractive map). AutoCM was already applied in medical field with extraordinary results (Buscema, 2007b; Buscema & Grossi, 2006; Buscema, Grossi, Snowdon, & Antuono, 2008; Buscema, Helgason, & Grossi, 2008; Licastro et al., 2008).

This method of data mining is an analytical process designed to search a data base for consistent patterns and/or systematic relationships between variables. The method aims to detect patterns from new subsets of data. The ultimate goal of data mining is to discover hidden trends and associations among variables.

AutoCM system, therefore, defines a square matrix of values describing the linear and the non-linear association strengths among all the dataset variables. We have chosen to filter this association’s matrix with the MST (minimum spanning tree), to generate an easy readable map, enhancing the fundamental links among the variables. The MST algorithm finds a minimum spanning tree for a connected weighted graph. MST method finds a subset of the edges that forms a tree that includes every vertex (variable), where the total weight of all the edges in the tree is minimized.

The AutoCM method is a new mathematical approach being able to point out the relative relevance of each variable in representing a major biological hub. This new paradigm of variable processing aims at creating a semantic connectivity map, in which:

(1) Non-linear associations are preserved;

(2) Connections schemes are explicit;

(3) The complex dynamics of adaptive interactions is captured.

This method is based on an artificial adaptive system being able to define the association strength of each variable with all the others in any dataset. Also, in this case, we have used a set of special research software designed by Semeion Research Center (Buscema, 2007a, 2008d; Massini, 2007).

This approach highlights affinities among variables as related to their dynamical interaction rather than their simple contingent spatial position. This approach describes a context typical of living systems where a continuous time-dependent complex change in the variable value is present. After the training phase, the matrix of the AutoCM represents the warped landscape of the dataset. A simple filter (minimum spanning tree by Kruskal, 1956) is then applied to the matrix of AutoCM system showing the map of main connections between and among variables and the principal hubs of the system. These hubs can also be defined as variables with the maximum amount of connections in the map.

Results and Discussion

After the identification of those variables which are more deeply affecting the global SIS index score, that means predictable of the 89% of the whole support need (see Table 2), a second analysis has been performed, trying to discover the reciprocal interactions among the same variables.

Table 2

The Most Significant SIS Variables After Supervised Networks Application

No.	Single item	Complete item description
1	AD_Ug_f	Home living_using the toilet_frequncy
2	AD_Ug_d	Home living_using the toilet_daily support time
3	AD_Pp_d	Home living_preparing food_daily support time
4	AD_Cp_f	Home living_eating food_frequency
5	AD_Cp_d	Home living_eating food_daily support time
6	AD_Rc_d	Home living_housekeeping and cleaning_daily support time
7	AD_Rc_T	Home living_housekeeping and cleaning_type of support
8	AD_V_f	Home living_dressing_frequency
9	AD_Fb_f	Home living_bathing and taking care of personal hygene and grooming needs_frequency
10	AD_Fb_d	Home living_bathing and taking care of personal hygene and grooming needs_daily support time
11	AD_Ae_d	Home living_operating home appliances_daily support time
12	VC_St_f	Community living_getting from place to place_frequency
13	VC_St_t	Community living_getting from place to place_type of support
14	VC_Pa_f	Community living_partecipating in recreation/leisure_frequency
15	VC_Pa_t	Community living_partecipating in recreation/leisure_type of support
16	VC_Sc_d	Community living_using public services_daily support time
17	VC_Vf_t	Community living_going to visit freinds and family_type of support
18	VC_Ac_d	Community living_partecipating in preferred community activities_daily support time

(to be continued)

19	VC_S_d	Community living_shopping and purchasing goods_daily support time
20	AP_Ia_d	Lifelong learnnig_interacting with others_daily support time
21	AP_Pd_f	Lifelong learning_partecipating in training/decision_frequency
22	AP_Pd_t	Lifelong learning _partecipating in training/decision_type of support
23	AP_Ps_f	Lifelong learning _learning problem solving_frequency
24	AP_Ps_t	Lifelong learning _learning problem solving_type of support
25	AP_Aa_t	Lifelong learning _learning health and physical education skills_type of support
26	Ap_Au_f	Lifelong learning _self-determination skills_frequency
27	AP_Ga_d	Lifelong learning _self-determination skills_daily support time
28	AP_Ga_t	Lifelong learning _self-determination skills_type of support
29	Oc_Fl_d	Employement_accessing/receiving job/task accomodation_daily support time
30	Oc_Al_t	Employement_learning and using specific job skills_type of support
31	Oc_Ic_d	Employement_interacting with co-workers_daily support time
32	Oc_Is_t	Employement_interacting with employers_type of support
33	OC_Ra_f	Employement_completing work-related tasks with accettable speed_frequency
34	OC_Ra_t	Employement_completing work-related tasks with accettable speed_type of support
35	OC_Qa_d	Employement_completing work-related tasks with accettable quality_type of support
36	OC_RI_f	Employement_changing job assignement_frequency
37	OC_Ri_d	Employement_changing job assignement_daily support time
38	OC_Ri_t	Employement_changing job assignement_type of support
39	Ss_Af_d	Health and safety_taking medication_dailly support time
40	Ss_Ep_d	Health and safety_avoiding health and safety hazards_dailly support time
41	Ss_Ep_t	Health and safety_avoiding health and safety hazards_type of support
42	Ss_Cg_d	Health and safety_ambulating and moving about_dailly support time
43	Ss_Se_f	Health and safety_learning how to access emergency services_frequency
44	Ss_Se_d	Health and safety_learning how to access emergency services_daily support time
45	Ss_Sb_f	Health and safety_maintaining physical health and fitness_frequency
46	Ss_Sb_t	Health and safety_maintaining physical health and fitness_type of support
47	Ss_Be_d	Health and safety_maintaining emotional well being_daily support time
48	As_Sf_t	Social activies_socializing within the family_type of support
49	As_Se_f	Social activies_socializing outside the family group_frequency
50	As_Ma_f	Social activies_making and keeping friends_frequency
51	As_Ma_t	Social activies_making and keeping friends_type of support
52	As_Cb_f	Social activies_communicating with others about personal needs_frequency
53	As_Cb_d	Social activies_communicating with others about personal needs_daily support time
54	As_Cb_t	Social activies_communicating with others about personal needs_type of support
55	As_Rs_f	Social activies_engaging in loving and interpersonal relationships_frequency
56	As_Av_f	Social activies_engaging in volonteer works_type of support

The purpose of this study is also to introduce in a preliminary way these innovative approaches in the field and research about ID. A general view of this application in the field of psychosocial research of ID is illustrated in case 1. A more focused view is offered in cases 2 and 3.

Case 1: Analysis of Total Scores

The application of this first data processing takes into consideration the whole of the 19 research variables (the sum of the SIS subscales in addition to demographic variables shown in Figure 1) and leads to the first result. The individual global support need is organized around a very small number of hubs, strongly clustered, with a number of links much higher than all the other junctions. Figure 1 shows graphically link and proximity

among the SIS sub-scores and all other independent variables analyzed in ANFFAS (National Association of Families of People with Intellectual and Relational Disabilities) data set.

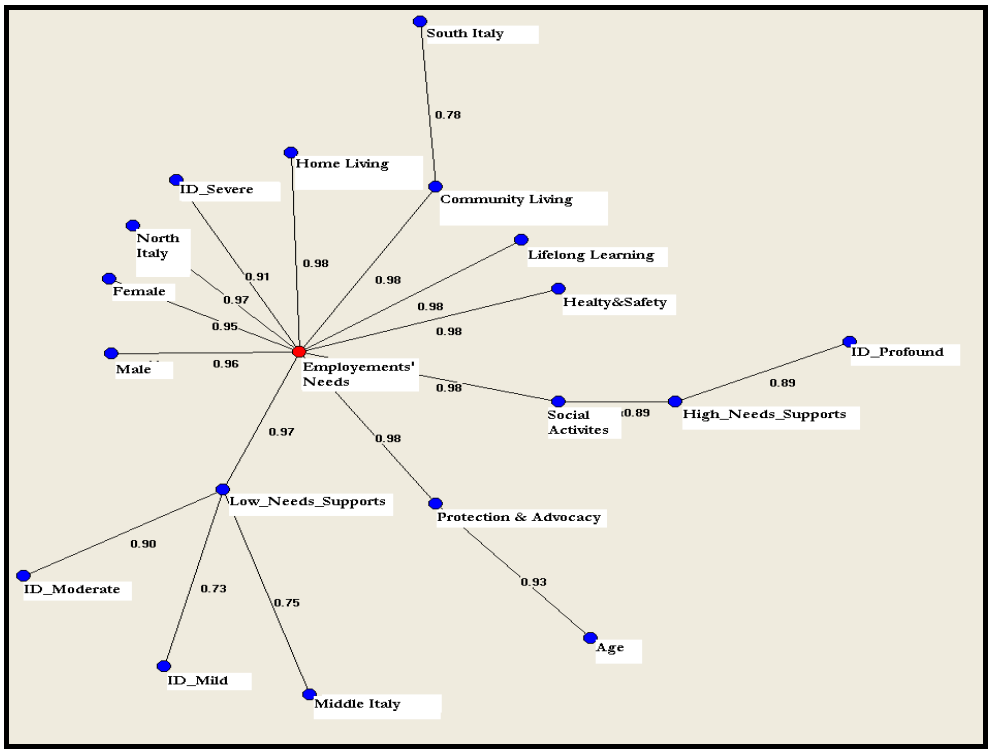

Figure 1. Total scores (References for other maps are in Table 2).

It is clearly a very centralized net with a four-degree maximum of separation (Jeffrey & Milgram, 1969) and a "core" in only one hub, represented by employments' needs. Some external variables, such as territorial localization (in Italy, this is a well rooted geo-economic reality) and even a consistent part of clinical diagnosis seem to be not directly linked to the central hub. If it is possible to find a global understanding of this analysis, it is clear that to modify the greatest numbers of variables determining the global need of support, intervention in the area of occupancy is really crucial and prioritary.

In the considered data set, there are 56 junctions, each of which is representative of the most important variables reported in Table 2. Each variable has an average of 1.9 links with an extension ranging from a minimum of one link, necessary to belong to the index construct, to a maximum of 15 links, represented by the central hub. Figure 2 reports the percentage distribution of link numbers for different items. Fifty-three percent of the considered items show only one link, while 27% shows two links.

Table 3 shows a strong variable asymmetry among the different number of links for different variables considered as a whole, while Figure 3 visualizes their distribution.

Plotting all the variables shows a greater number of details as is displayed in Figure 4 and drives to think a lot of different data interpretation and understanding. The topographic examination of the variable map shows that really inside the support need construct, there are two different structures connected only by the link with the central junction.

Case 2: General Map of All the Significant Variables After TWIST Application

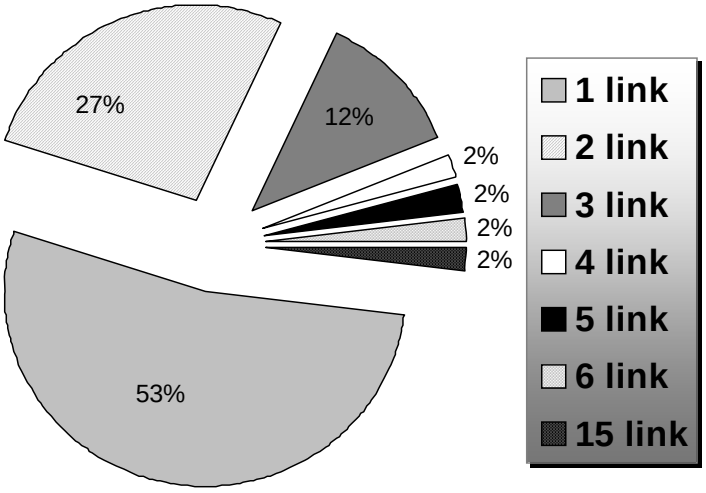

Figure 2. Percentage distribution of link numbers for the short SIS version items.

Table 3

List of the Most Connected Items

Items	Number of links
Lifelong Learnig_Learning health and physical education skills_type of support	15
Health and Safety_Maintaining physical health and fitness_type of support	6
Employement_Completing work-related tasks with acceptable speed_type of support	5
Social Activies_Making and keeping friends_type of support	4
Employement_Completing work-related tasks with acceptable quality_type of support	3
Employement_Accessing/receiving job/task accomodation_daily support time	3
Lifelong Learning_Self-determination skills_frequency	3
Home Living_Using the toilet_frequency	3
Lifelong Learning_Learning problem solving_type of support	3
Home Living_Bathing and taking care of personal hygene and grooming needs_frequency	3
Community living_Getting from place to place_frequency	3

The central hub is a sort of “trait d’union”, the emerging root of the entire network, i.e., the item that analyzes the type of support of lifelong learning in health and physical education skills (total or partial physical assistance, etc.).

From a perspective of scale-free network, it is not surprising that the most frequently connected junctions refer to basic support needs. These support needs reflect primary respect of human surviving, and presumably, they are the first ontogenetically generated. All the other needs of support seem to emerge from these primary ones.

Anyway, what comes out from plotting the variable connections is a decentralized net with a clean distinction in two different central regions. Region B is at its own rooted in distinct areas. Two clusters in region B appear better defined, grouping some of the proposed variables. They are social activities together with health and safety activities and employment activities. Region B contains a greater number of rooted junctions.

An extended ramification is present and more than 50% of the observed variables are connected with only one link, and in the meantime, a series of very connected clusters are observed.

These hubs represent the core of the considered construct. At an operational level, the core construct suggests the chance to identify in a critical core of variables, the most incident factors of intervention with potential consequences on all the connected variables.

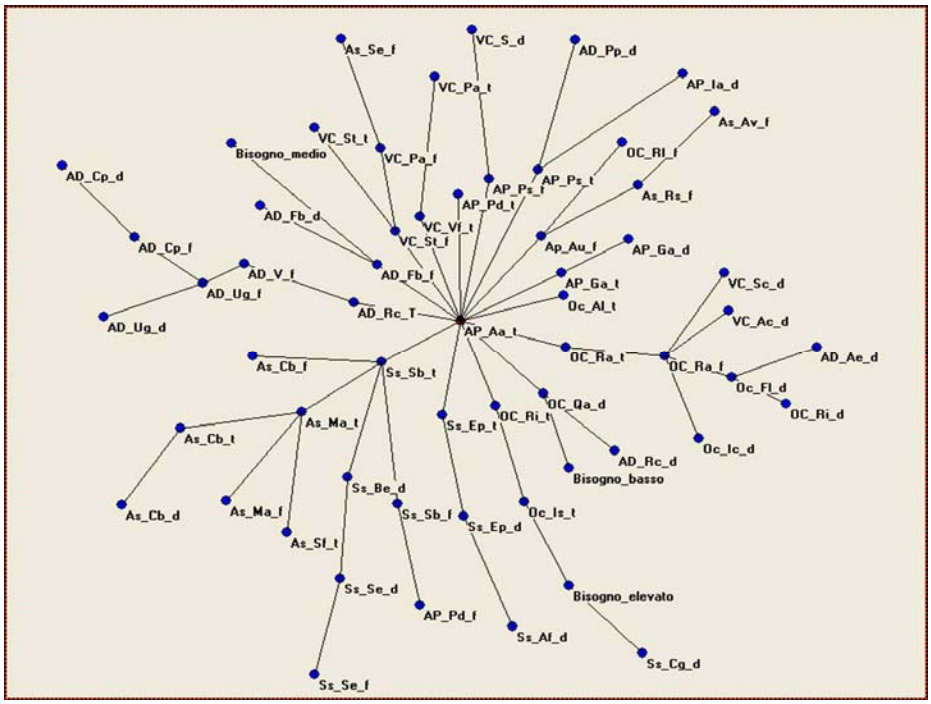

Figure 3. The general map.

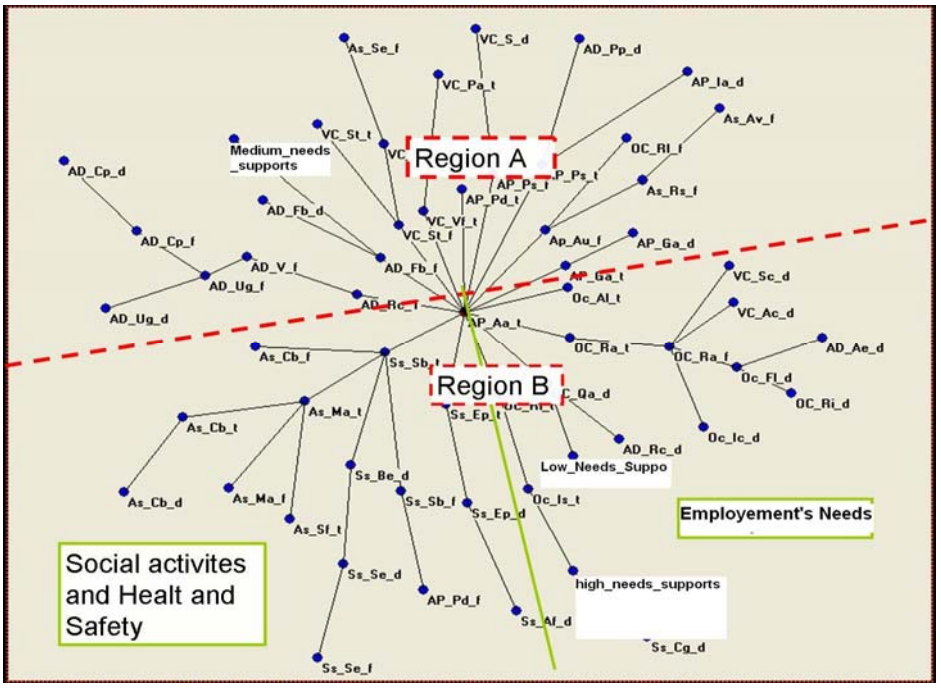

Figure 4. Schematic subdivision map.

In other words, the map configuration identifies the core variables on which services plan intervention in order to amplify outcomes to the widest areas of support, the connected variables. Once we have an objective, it is easy to understand the direction of support implementation on the basis of core connected variables of support needs. Figure 4 represents a schematic vision of the same analysis reported in Figure 2, as it is

proposed in the general map.

In any case, it must be noticed that there exists a great degree of separation between the most distant variables. This observation reinforces the multidimensional attribution to the construct of "need of support". Consequently, it is plausible to surmise that the general construct of SIS is determined by the contribution of many different components.

Case 3: A Detail

The same previous processing has been re-proposed in a smaller, limited group (a subgroup of the standard sample N* 845 subjects out of 1,052), with age under 45 years.

This focalization demonstrates with the maps how variables can be connected in more specific subpopulations, even when the subpopulation group gets the individual subject. The consequences to individual planning might be really strategic. It is quite easy to find the differences between Figure 5 and Figure 3. Also, in this second case, we are at the presence of a centralized network, but the central hub is not the same junction as before. The variable with a greater number of links in Table 2 is not the same central variable as in Figure 5. The last one is the root of three clusters that contend the links with all the other variables. Each of the three cluster marks a different route.

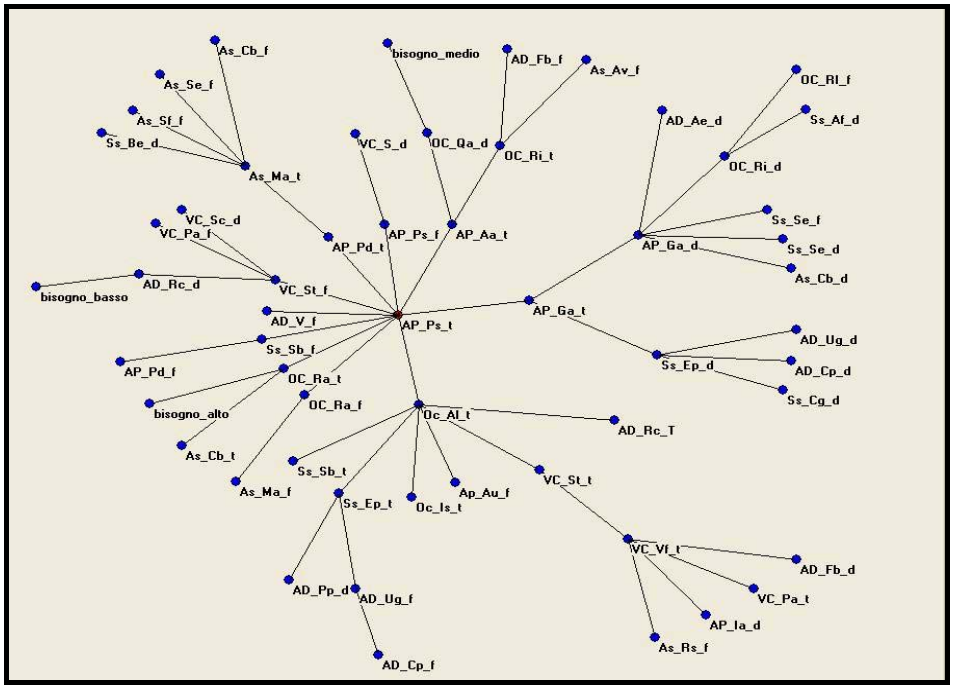

Figure 5. Map of the subjects less than 45 years of age.

Conclusions

One of the most evident limitations of traditional statistic approach is demonstrated by considering each variable individually or, at the most, by couples and postulating the paradigm of a normal distribution of such variables. However, there is growing evidence in human sciences that traditional statistical analyses cannot embrace the effective interaction complexity and typical of natural environments.

The relations of the constructs of QoL and well being for people with ID are very complex, implying inevitably a complex support network which aimed at ameliorating QoL and well being in the population. The bio-psycho-social model complexity might be explained only in a very rough and approximate way by

traditional models of statistic analysis of data (Szalay & Gray, 2006) collected by means of scales, such as SIS. The perspective of well being and QoL for people with ID, drives the efforts to introduce more complex models to explain the network-based interactions of supports and needs of support.

The issue concerning potential or effective data non-linearity has been really not faced by biomedical and psychosocial scientific literature. These non-linear systems are quite easy to be understood and that is the main reason why they have been so successful. Actually, linearity, taken as the current model, supposes that the magnitude of the answer is proportional to the intensity of the stimulation. They both—magnitude of the answer and intensity of the stimulation—may be clearly understood by determining their own components. In this way, the sub-unities of a linear system may be simply summed and, consequently, no surprises or abnormal behaviors are expected.

On the other hand, when non-linear systems are involved, the proportionality concept is not still valid. It should be considered that all the complex systems are not linear (Wang & Chen, 2003).

Even small changes may produce terrific effects and consequences, which may not be foreseen in advance. They may not be understood by analyzing each of their individual components.

Moreover, the higher the complexity of psychobiological and social systems is, the higher the inadequacy of the linear system approach is. If we think of a complex system as a linear system, we simplify conditions, processes and phenomena, obtaining a wrong vision of what really happens.

What is the model representing such a reality at its most?

How is it possible to understand and manage in a rational way, some of the connections among the different variables? How is it possible to determine the specific impacts of each of them?

Looking from a multidisciplinary perspective at the most recent scientific theories in biological (Wagner, Amemiya, & Ruddle, 2003; Wagner et al., 2005a; Wagner, Mezey, & Calabretta, 2005b) and in quantity mechanics fields (Barabási & Bianconi, 2001), we refer to the scale-free network model and the mathematical algorithm that gets the nearest to the obtained data is linked to the potency law (Bak, 1996).

In order to probe the validity and effectiveness of this revolutionary way to analyse data derived from SIS, we intend to conduct a one-year multicentre randomized controlled single-blind trial during which an individualized support need programme will be applied to persons with ID. In the experimental group interventions will be based on SIS information analysed by means of artificial adaptive systems, whereas control subjects will be supported with programmes derived from the traditional SIS indexes. The primary outcome of the study will be QoL of people with ID, the secondary outcome will measure the degree of job satisfaction of the professional caregivers.

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