Concept mapping for the evaluation of public policies. Application to the effects of the Spanish Dependence Act on informal caregivers

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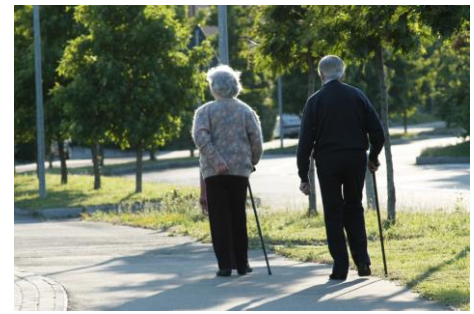
Background: Informal care and the Spanish Dependence Act (*Ley de Dependencia*)



In Spain, it is estimated that there are 2 million dependent people[1].

In 80-88% of the time the care they receive is informal, i.e. done by their relatives or friends, who don't receive any payment[2].

Informal caregivers are usually women, aged 45 to 65, with a low educational level and mostly unemployed[1].

Informal care has a cost in the quality of life of caregivers[3,4] and because of its unequal social distribution, it acts as a determinant of health inequalities[5].

The Act's goal: universal rights and access to services and social care for individuals requiring long-term care. Passed by the Spanish goverment in 2006, it has been a paradigm shift in public services and facilities for dependents and recognition of informal caregivers.

[1]Esparza C. Discapacidad y Dependencia en España. Madrid: Informes Portal de Mayores,Nº108; 2011.
[2]IMSERSO. Libro Blanco. Atención a las personas en situación de dependencia en España. Madrid: Ministerio de Trabajo y Asuntos Sociales e IMSERSO, 2005.
3Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis.Psychol Aging 2003;18:250-267.
[4]Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. Am J Nurs 2008 Sep;108(9 Suppl):23-7; quiz 27
[5]Larranaga I et al. Impact of informal caregiving on caregivers' health and quality of life: analysis of gender inequalities. Gac Sanit 2008 Sep-Oct;22(5):443-450.

STUDY OVERVIEW

Object of study: The impact of the Dependence Act on informal caregivers' quality of life

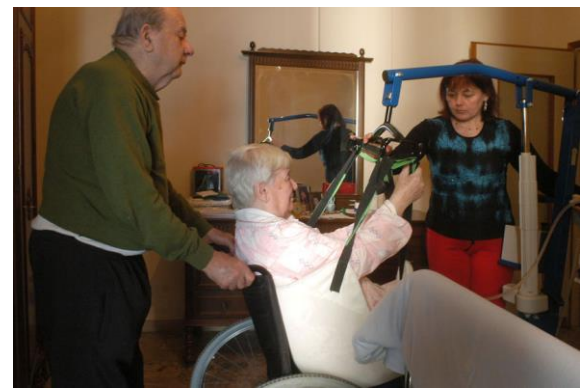
Research Questions

•Caregivers' and Primary health care professionals' perceptions towards the mechanisms of how the Dependence Act affects the caregivers' quality of life.

•Assessment of the perceptions of importance, satisfaction and frequency of these mechanisms.

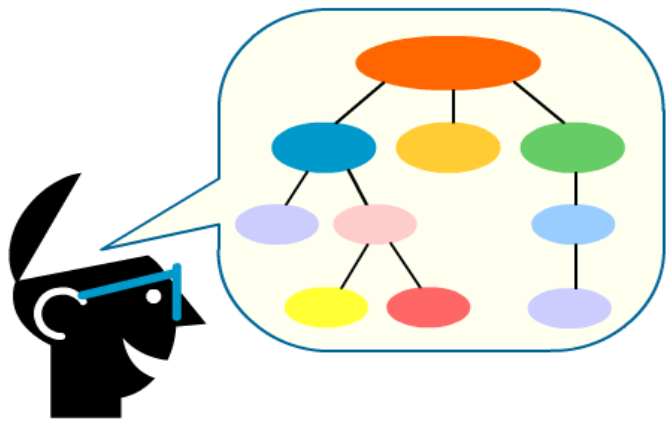
•What the differences between caregivers' and professionals' perceptions are.

Objective of the study: To assess the mechanisms through which the Dependence Act can influence the caregivers' quality of life, according to their own perceptions and those of the Primary Health Care professionals.



CONCEPT MAPPING

- Non-traditional qualitative approach.
- Developed in the late eighties by William M. K. Trochim as a management tool in organization.
- It was later adapted and modified for public health in the early 2000s.
- Allows for a more objective and reliable analysis of data
- It provides a conceptual framework that depicts how a group or a population perceives a particular situation.



Trochim, W.M.K., Kane, M. (2007) Concept Mapping for Planning and Evaluation. USA: Sage Publications.

CRICH Survey Research Unit. (2011) 3 Day Concept Mapping Training Course. Canada: St. Michael's Hospital.

CONCEPT MAPPING

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Data Collection and Analysis Procedure:

Step 1: Development of focus question.

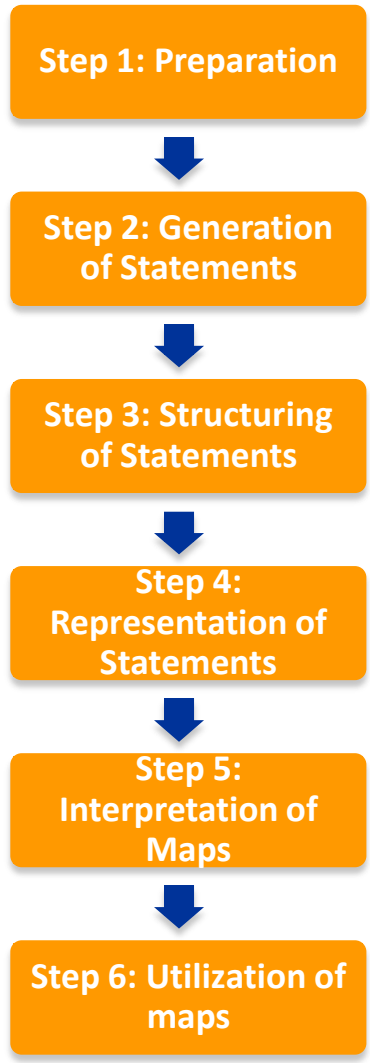
Step 2: Brainstorming session to generate as many statements in relation to the focus question.

Step 3: Scoring and grouping of statements.

Step 4: Data analysis consisting of three stages, multidimensional scaling, hierarchical cluster analysis and the generation of cluster maps.

Step 5: Further analysis of statements and groups leading to the creation of the concept map.

Step 6: Discussion of maps and their contribution to the focus question.



Step 1: Preparation

Define the issue

•What are informal caregivers' and Primary Health Care professionals' perceptions of the Dependence Act effects on the caregivers' well-being?

Develop the focus question

• *"A way in which the Dependence Act has affected my quality of life is…"*

Develop the rating questions

•For caregivers : importance for their well-being and satisfaction

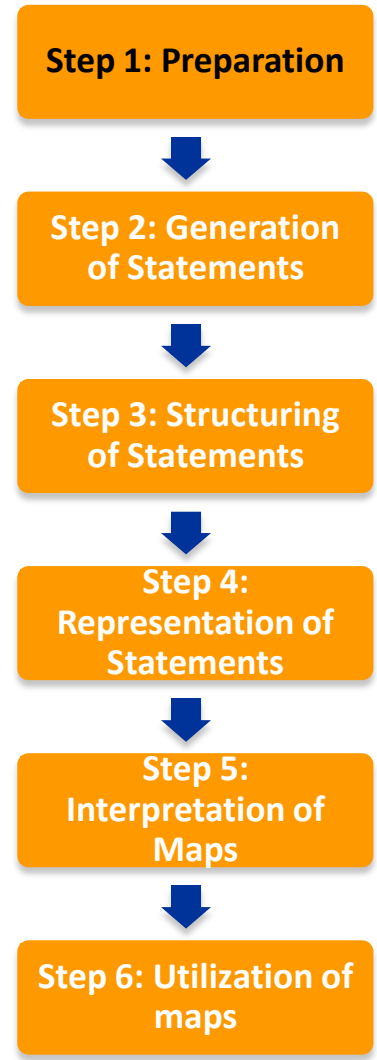
•For Primary health professionals: importance for the caregivers' well-being and frequency (how often it has happened)

Selection of participants

•Women caregivers of dependent people who have received benefits from the Act

•Primary Health Care professionals

•Both caregivers and professionals had developed their work before and after the Act was passed.



“Dependence Act”. Participants’ description

Four groups were created within 2 Primary Health Care Centers in Barcelona.

Caregivers (N=16 women)

Age (mean)	65,7 years (range: 46-79)
Education	31,3% Literate 50% Primary school 18,8% Secondary school
Employment	12,5%
Time of care	6,1 years (mean, range: 2-15); 81,25% care 24 hours/day 93,8% care 7 days/week
Relationship *	56,3% father/mother 50% couple 6,3% Father/mother in law (12,5% more than one person)
Reciving beniefits from the Act	1,8 years mean (range 0,5-6)
Benefits**	50% Economic help linked to family care 31,3% Home help 25% Economic help linked to the service 12,5% Telephone helpline 6,3% Day Center

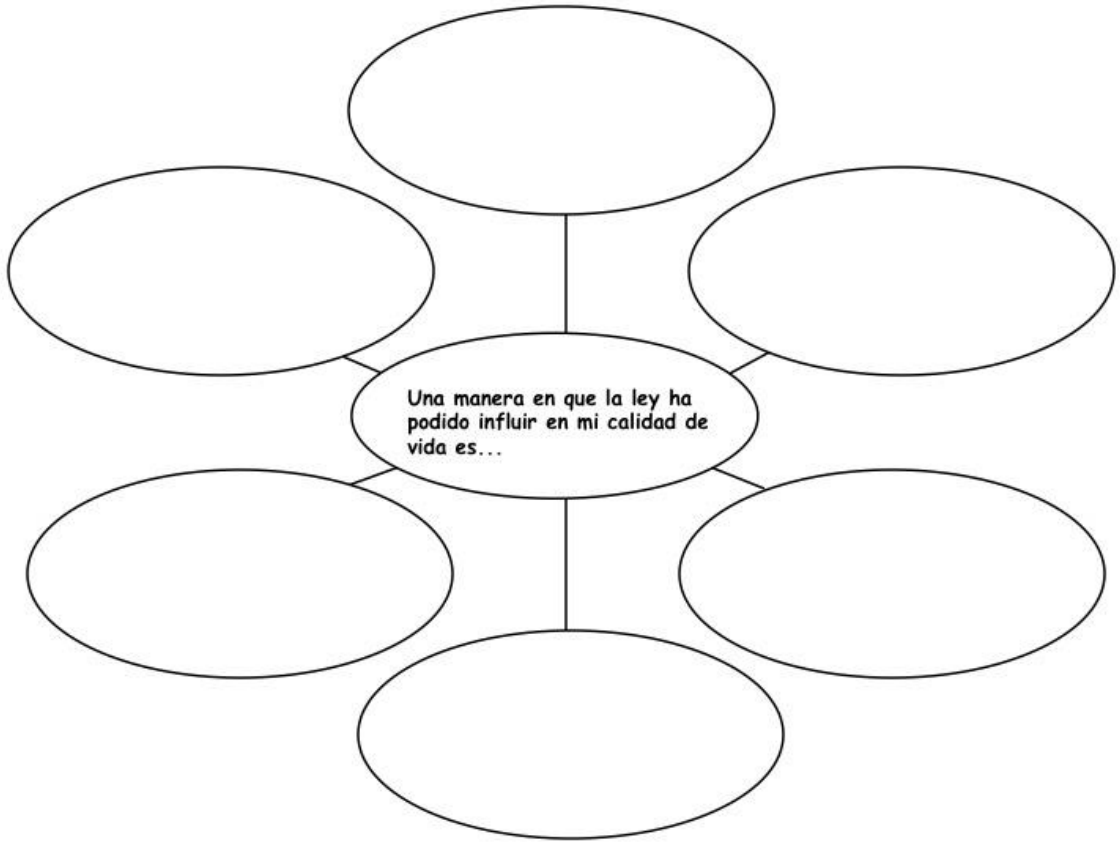
Health Professionals (N=21)

Age, mean (range)	42,2 years (28-57)
Sex	76% women
Profession	57% Doctors 38% Nurses 5% Social workers
Time working, mean (range)	12,6 years (4-30)

*There were participants who care for more than one person
** There were dependent persons who receive more than one benefit

Step 2: Generation of Statements

- *Brainstorming* session.
- Participants receive a «brainstorming sheet» in order to start thinking individually and take notes during the session.



Step 1: Preparation

Step 2: Generation of Statements

Step 3: Structuring of Statements

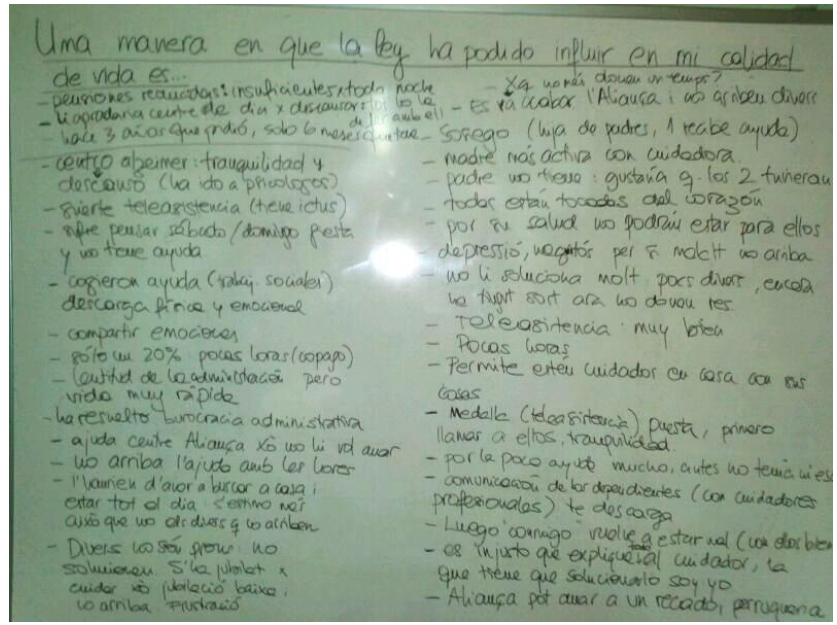
Step 4: Representation of Statements

Step 5: Interpretation of Maps

Step 6: Utilization of maps

Step 2: Generation of Statements

- One person from the research team moderates the session and another one writes down the ideas on a visible sheet or whiteboard.



- After the session, the draft list is reviewed and converted into a list of statements with unique ideas for the next steps of the process.

	Caregivers	Professionals
Final # of Statements	27	32

Step 1: Preparation

Step 2: Generation of Statements

Step 3: Structuring of Statements

Step 4: Representation of Statements

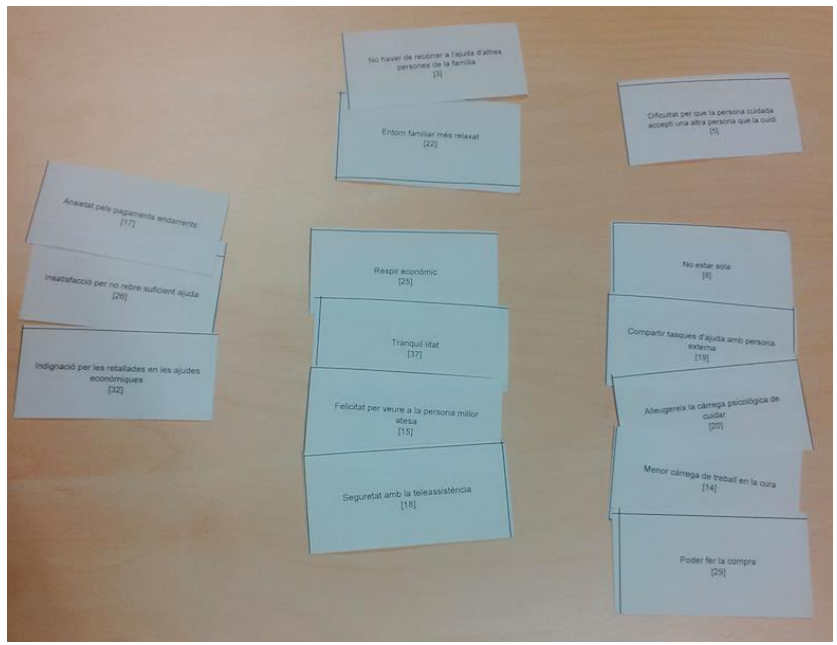
Step 5: Interpretation of Maps

Step 6: Utilization of maps

Step 3: Structuring of Statements

1. Sorting statements

- Participants were asked to sort statements into groups that made sense to them based on a common theme.
- No statement could be left alone and participants were encouraged to maintain groups with less than 7 or 8 statements if possible.



Step 3: Structuring of Statements

2. Rating statements

- Caregivers were asked to rate the statements based on importance for their well-being and also their satisfaction.
- Primary Health Professionals were asked to rate the statements based on importance for the caregivers' well-being and also its frequency.

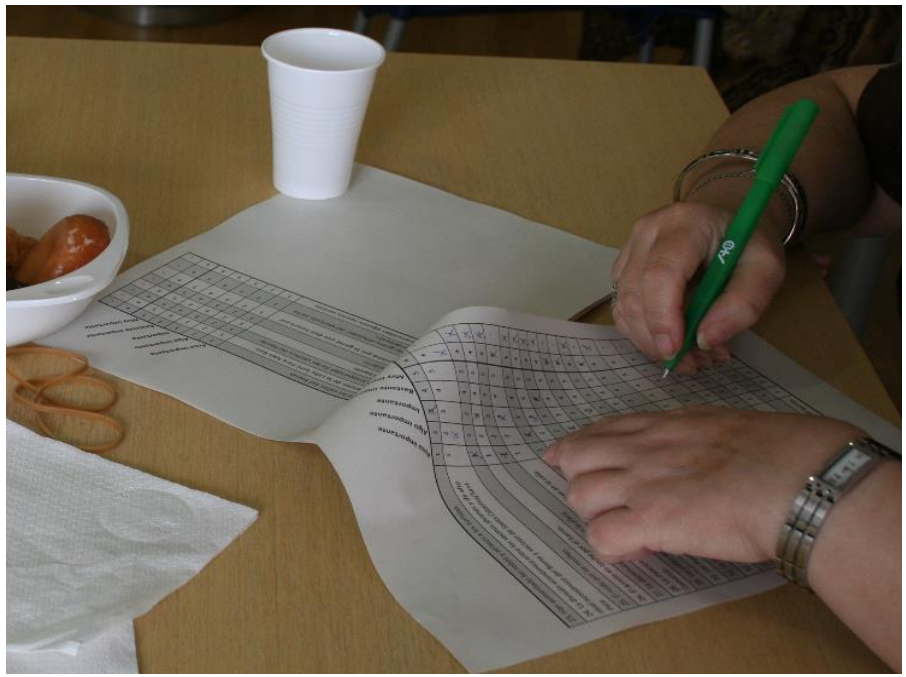
Aquí hay un listado de maneras en las que la Ley de Dependencia ha podido influir su salud y calidad de vida. Por favor, valoren según su opinión cada una de ellas del 1 al 5 siguiendo dos criterios, primero en función de la **importancia que tiene para su salud y calidad de vida y segundo su grado de satisfacción con cada uno de ellos**

	Importante						Satisfacción				
	Poco	Algo	Importante	Bastante	Muy		Poco	Algo	Satisfecha	Bastante	Muy
1. Poder contratar a otra persona	1	2	3	4	5		1	2	3	4	5
2. Continuar sintiéndose la principal responsable del cuidado	1	2	3	4	5		1	2	3	4	5
3. Frustración por los atrasos en el pago	1	2	3	4	5		1	2	3	4	5
4. Realizar tratamientos de salud propios	1	2	3	4	5		1	2	3	4	5
5. Poder dejar a la persona dependiente al cuidado de profesionales (personas o centros)	1	2	3	4	5		1	2	3	4	5
6. Dedicar tiempo al cuidado de una misma	1	2	3	4	5		1	2	3	4	5

Likert-like scaling system

Step 3: Structuring of Statements

Images from a Sorting and Rating session



Step 4: Representation of Statements

Data analysis phase (Concept Systems Software):

A. Similarity matrix from sort data

- Square symmetric matrix that shows the number of participants who sorted each pair of statements together in accomplishing their sorts.

B. Multidimensional scaling:

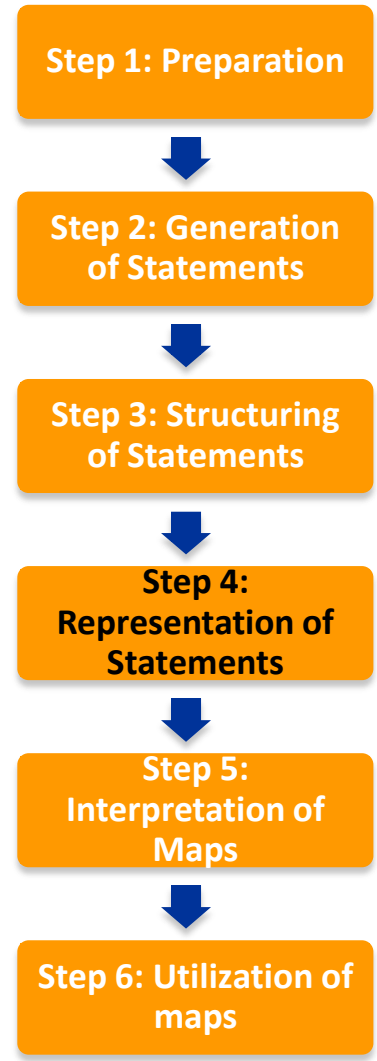
- Scaling of similarity matrix to locate each statement as a separate point on a two-dimensional (x,y) map (ie. Point map)

C. Hierarchical cluster analysis:

- Analysis of multidimensional scaling (x,y) coordinates to partition the points (statements) on this map into groups. (ie. Cluster maps)

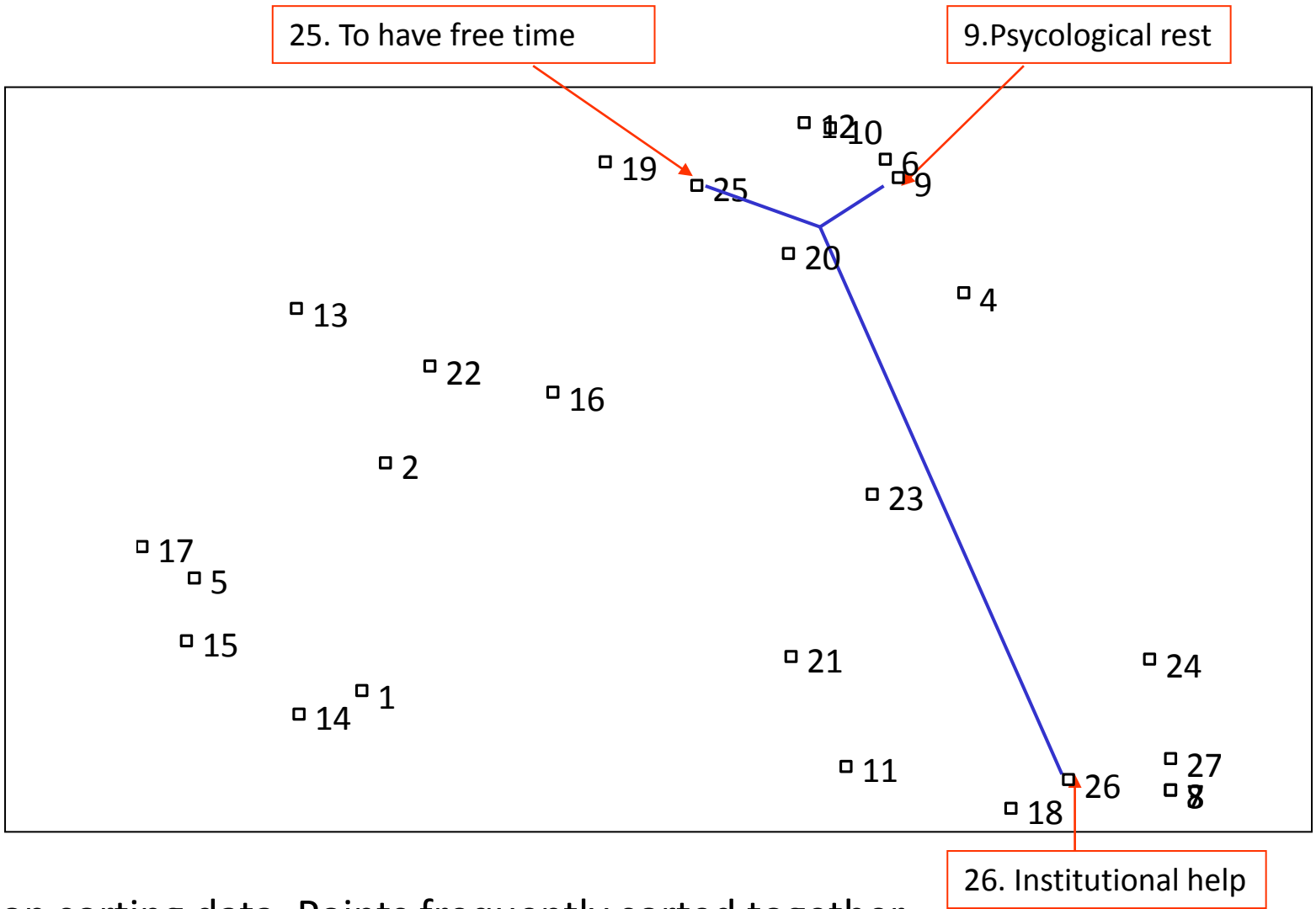
D. Pearson Correlation analysis:

- Bivariate plots, divided into four quadrants using the axes of two rating scales for the project (i.e. Go-zone)



Step 4: Representation of Statements

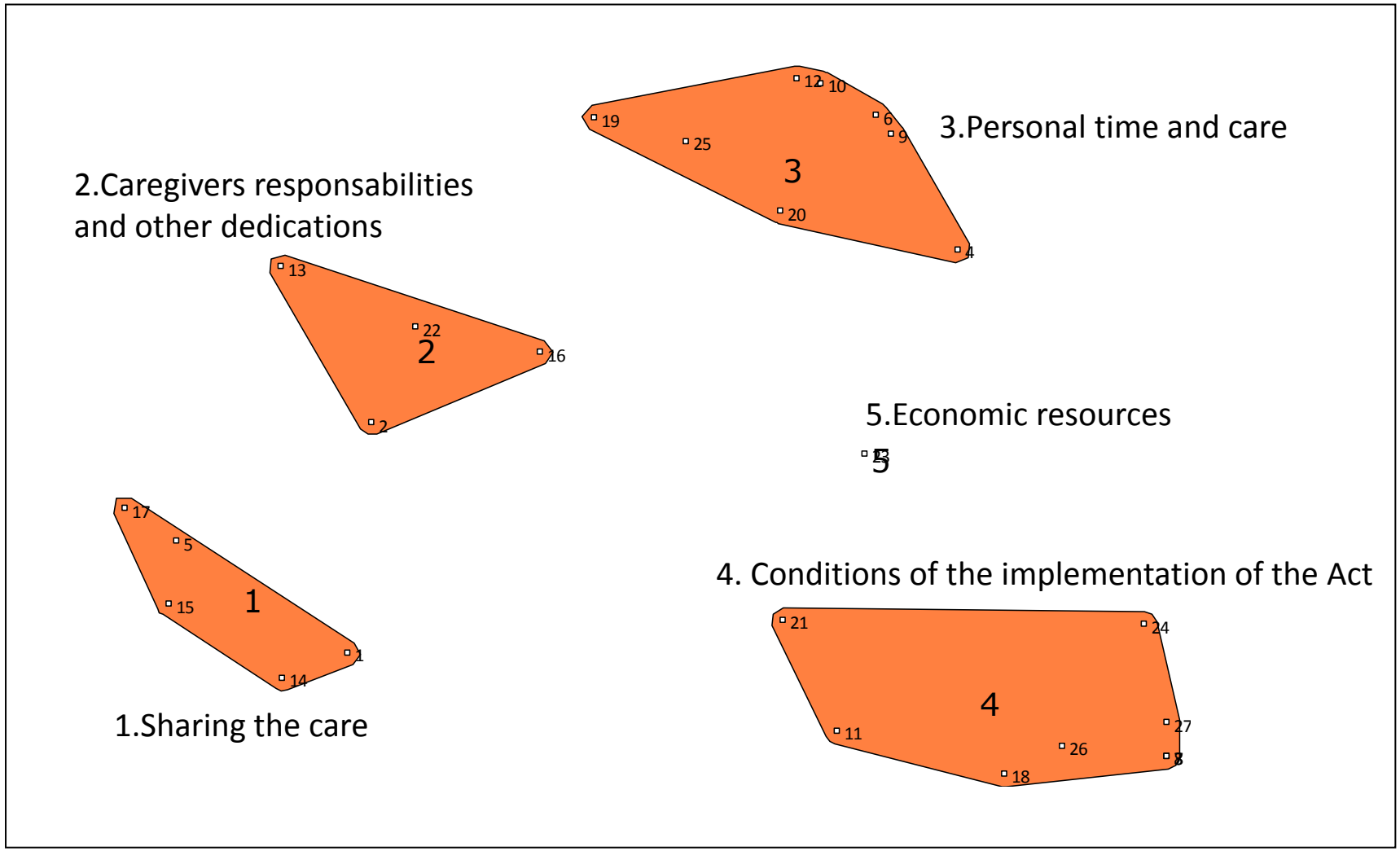
Point map of perceptions towards the Dependence Act by the caregivers



Based on sorting data. Points frequently sorted together are near, points never sorted together are far

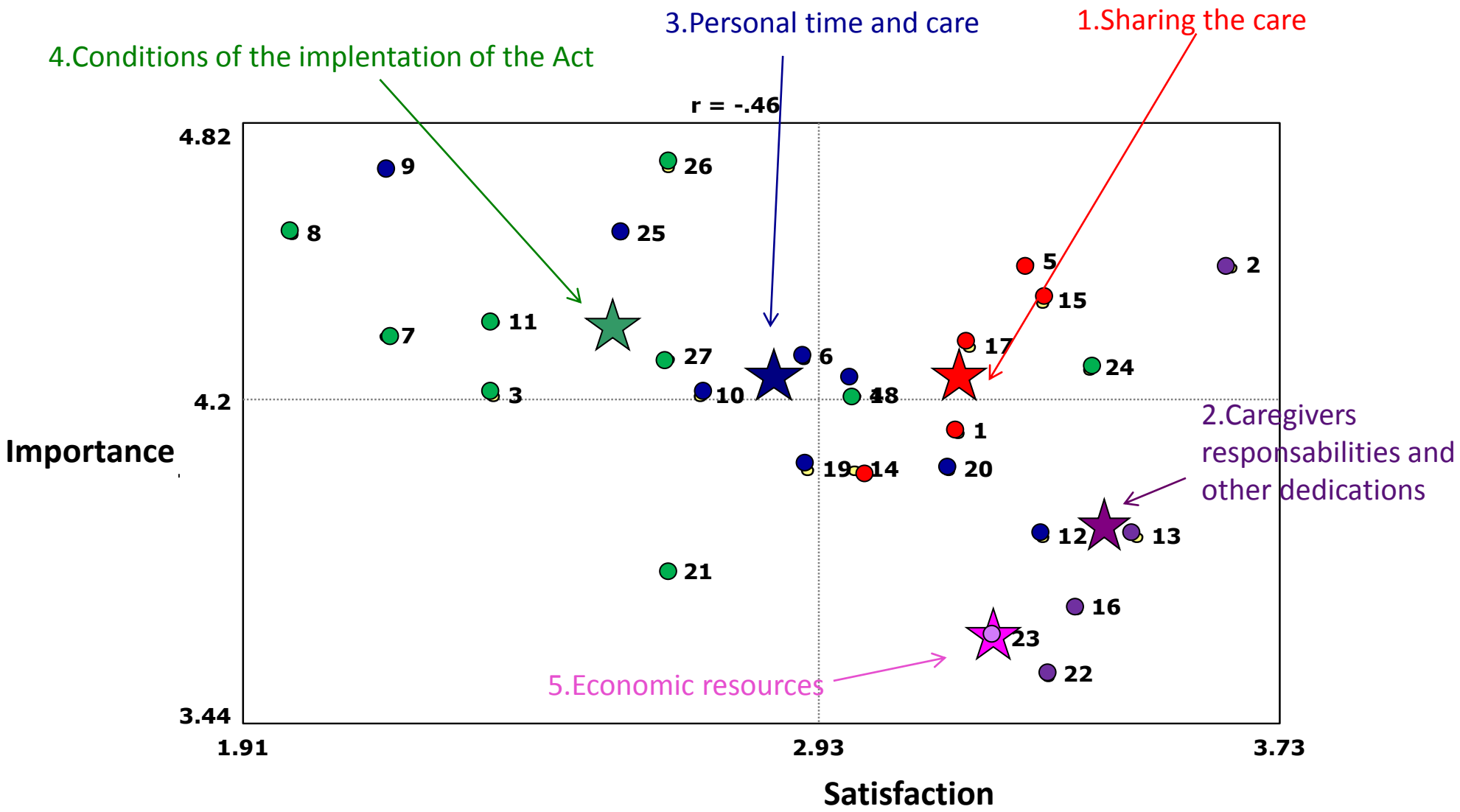
Step 4: Representation of Statements

Cluster map of perceptions towards the Dependence Act by the caregivers



Step 4: Representation of Statements

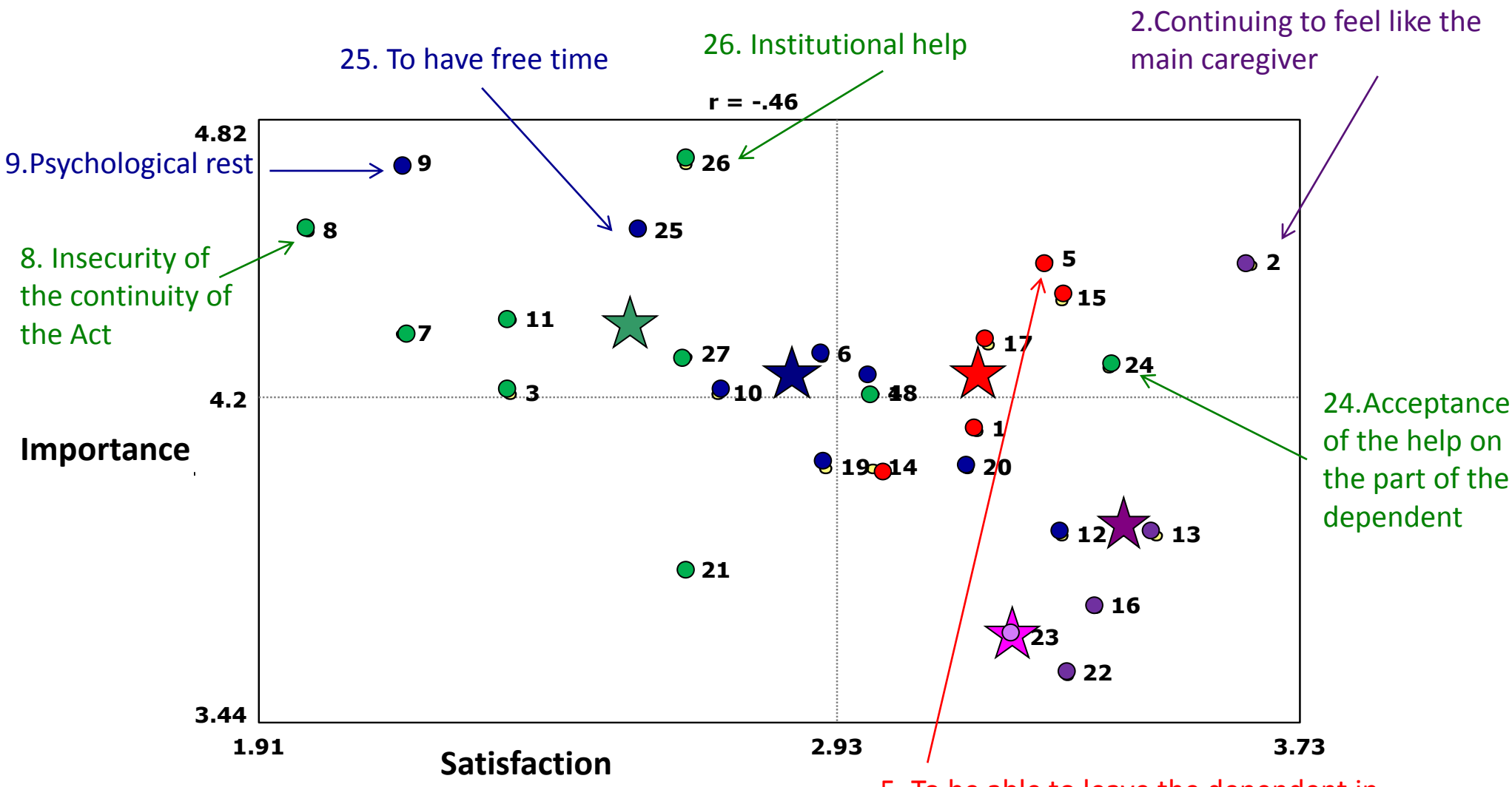
Go-Zone of ratings of statements and clusters by caregivers



Based on rating data. Stars represent clusters average ratings. Points represent statements and are coloured by cluster.

Step 4: Representation of Statements

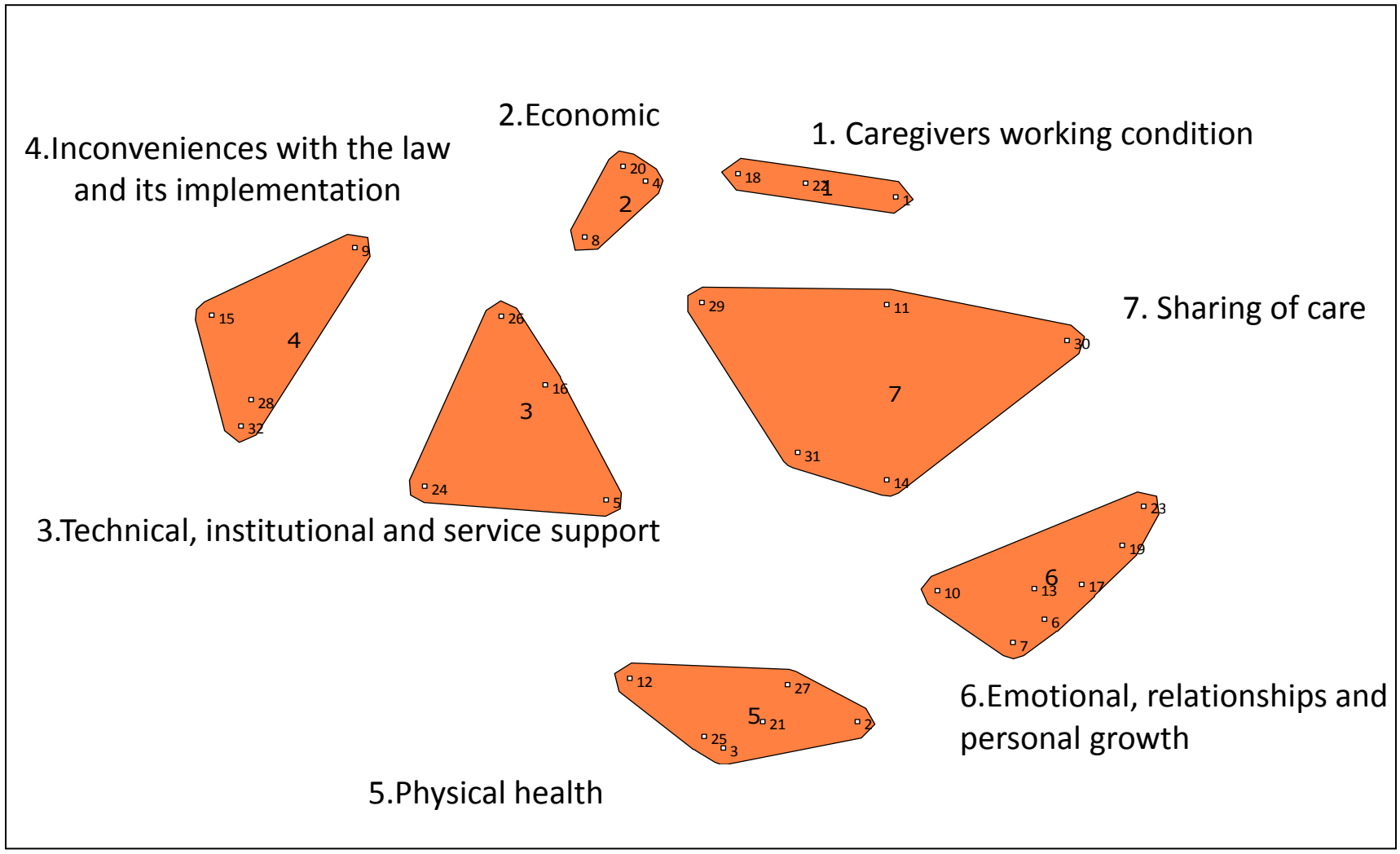
Go-Zone of ratings of statements and clusters by caregivers



The upper-left quadrant includes items where improvement is needed (very important but unsatisfactory).

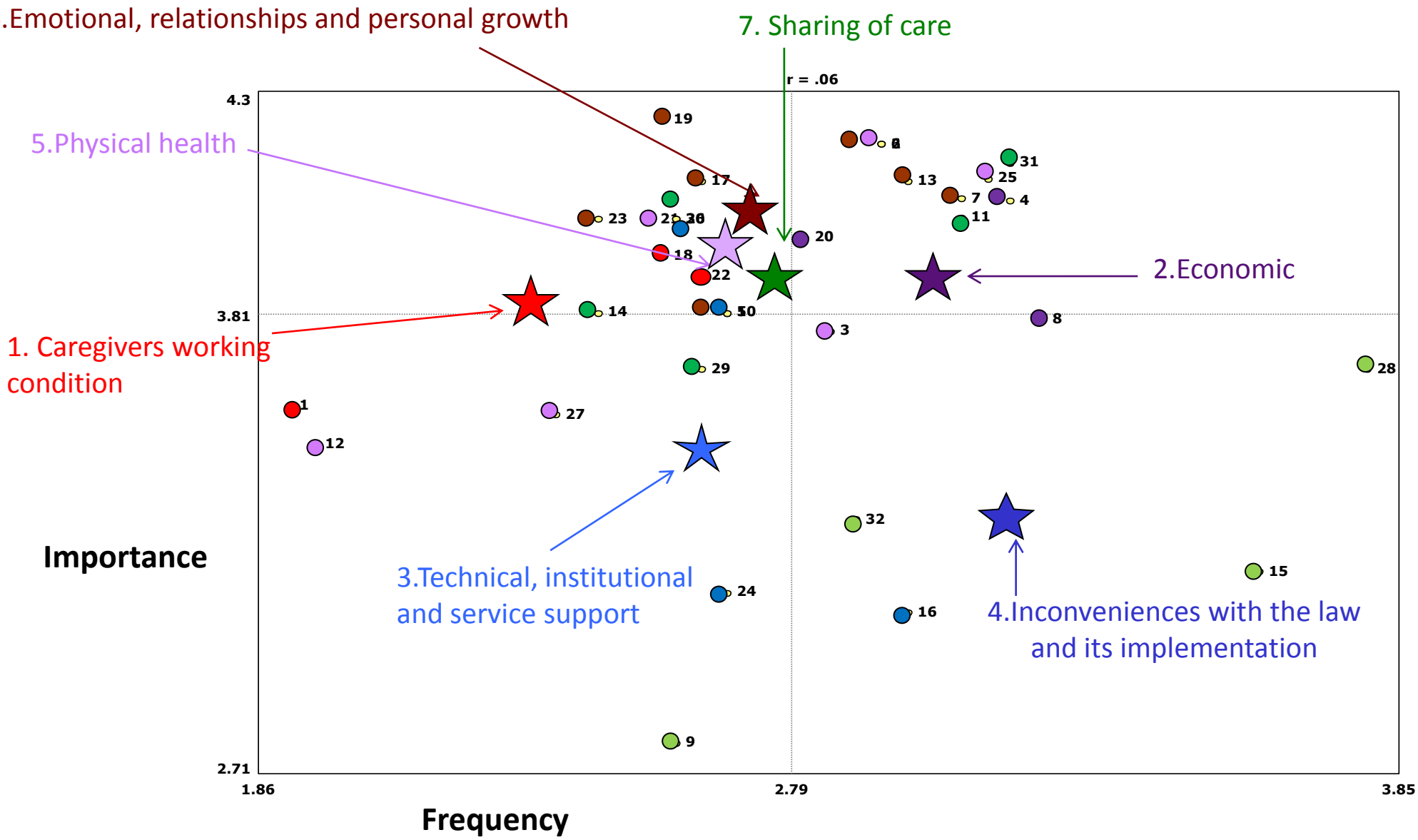
Step 4: Representation of Statements

Cluster map of perceptions towards the Dependence Act by primary care professionals



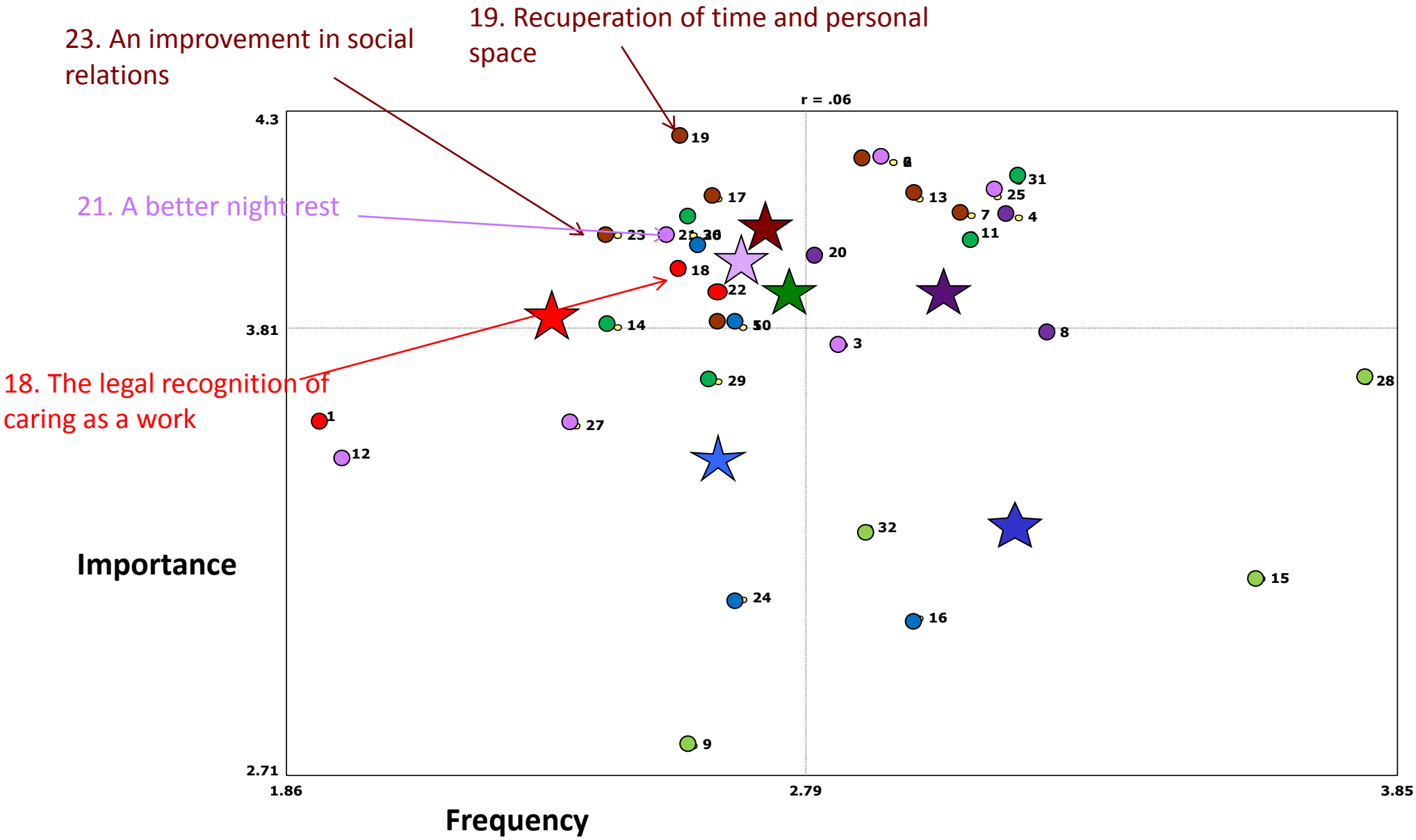
Step 4: Representation of Statements

Go-Zone of ratings of statements and clusters by health professionals



Step 4: Representation of Statements

Go-Zone of ratings of statements and clusters by health professionals



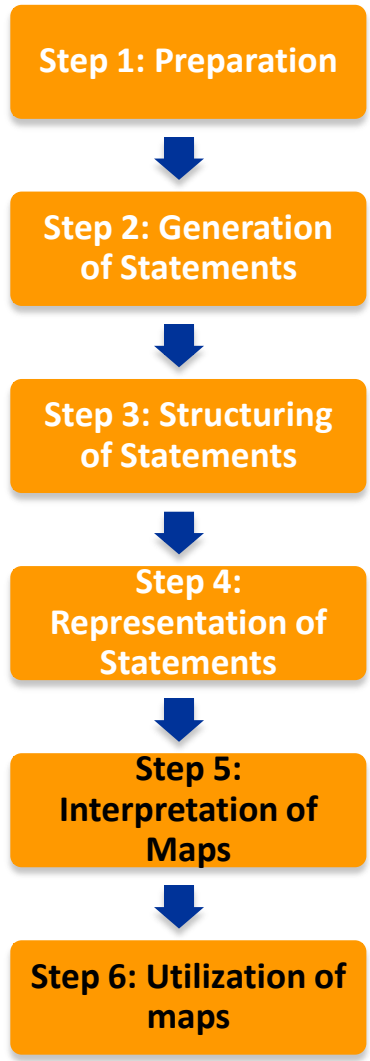
Step 5&6: Interpretation & Utilization of maps

Step 5: Interpretation of maps by participants:

- In a third session, participants are shown the maps.
- Clusters boundaries can be redrawn and names can be assigned to clusters.
- Part of the validation process as the maps are the result of participants' ideas.

Step 6: Utilization of maps:

- Usage of maps for reports and presentation to community, stakeholders and government.
- Go-zone useful for identifying areas for improvement (high importance, low satisfaction/frequency).



Strengths and Limitations

Strengths:

- Usage of quantitative analysis to produce maps that illustrate how a group views a specific topic or issue (and compare groups).
- Easy to interpret and useful for displaying factors that are perceived by participants and their importance relative to the issue at hand.
- Incorporation of participants in the development and interpretation of the research data.
- Relatively fast process and analysis.

Limitations:

- Participation burden – three sessions (although not all participants need to participate to all of them).
- Activities can be challenging for individuals with reading difficulties.
- Intensive preparation activity before and between sessions.
- Limited to one focus question.

Some Methodology Tips

- Participant recruitment and retention is easier with an already established group.
- Piloting focus and rating questions is useful. Be clear with definitions.
- Materials for structuring session are time consuming.
- “Recommended” 50-70 statements is too much for community groups.
- Time period between sessions should not exceed 3-4 weeks.
- Incentives are useful when working with specific populations.

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