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**HSP AND QUALITY OF LIFE: THE
PERSPECTIVE OF PATIENTS AND
THEIR CAREGIVERS**

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Disability and subjective experience

The impact of disability is specific to how individuals perceive themselves and their lives (Lutz & Bowers, 2005)

A person-centered model needs to take into account

- 1) How persons with disability perceive
 - their health
 - their daily life
 - their social context

- 2) How caregivers perceive
 - their caring experience
 - their daily life
 - their social context

Patients' and caregivers' perception of illness

Individuals with disability

- Cope with severe stressful circumstances

However they can perceive

- A good quality of life
- Positive changes in personality
- Positive social relations

Cargivers

- Perceive stress according to the number of care hours

However

Family resilience promotes well-being

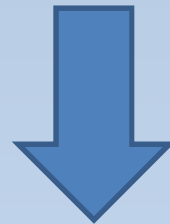
No sistematic studies have been conducted on the perceived quality of life among people with HSP and their families

Theoretical framework (1)

From the Eudaimonic perspective well-being

- **does not necessarily mean pleasure**
- **includes the human tendency to pursue meaningful goals**
resilience
social competencies

Interpersonal relations play a key role in fostering individual and community well-being



The relationship between perceived quality of life, meaning making, goal setting and pursuit, and social action should be explored (Keyes & Haidt, 2003)

Theoretical framework (2)

Within the Eudaimonic perspective optimal experience:

- **plays a key role in psychological selection**
- **promotes individual complexity and the increase of competencies**
- **Promotes personal growth and social integration**

The Study:

Aims:

- a) The association of daily activities with optimal experience;
- b) Wishes, daily challenges, and positive and negative life influences;
- c) The relation between daily context and eudaimonic well-being

Sample

33 patients with HSP

21 men and 11 women aged 18-74 (mean age=44)

13 were able to walk autonomously

20 needed wheelchairs or crutches

21 caregivers

5 men and 16 women aged 29 -79 (mean age=52)

Procedure:

Flow Questionnaire (FQ, Delle Fave & Massimini, 1991)

It investigates the activities associated with optimal experience through open-ended questions

Moreover it investigates participants' wishes

Life Theme Questionnaire (LT, Delle Fave e Massimini, 2004)

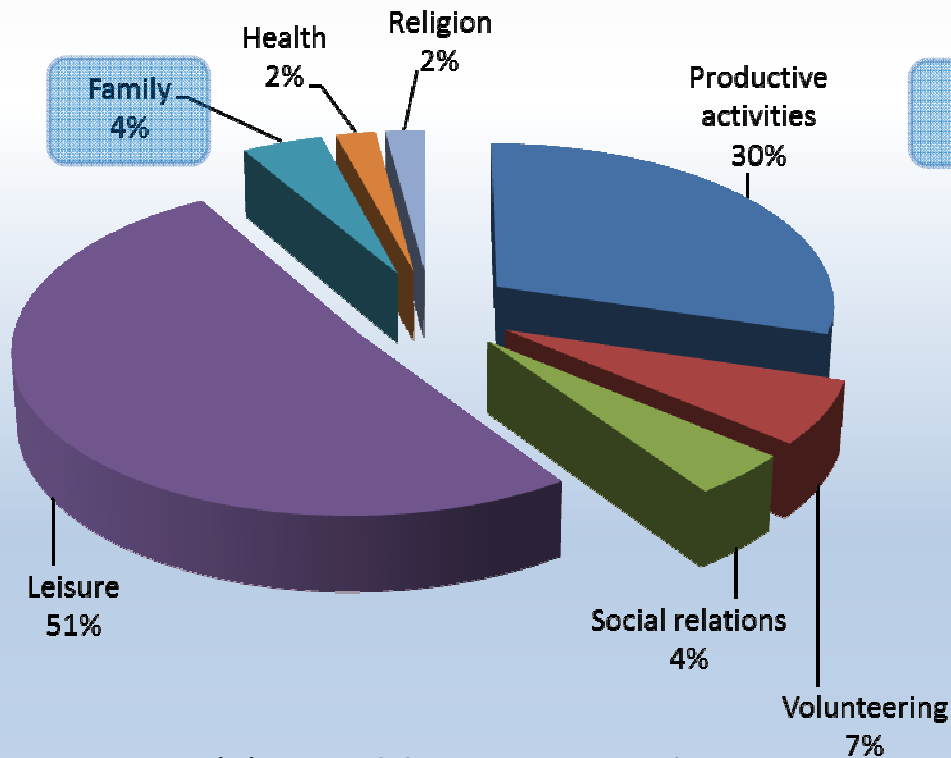
It explores through open-ended questions participants' positive and negative life influences and present challenges

Eudaimonic and Hedonic Happiness Inventory (EHHI, Delle Fave et al., 2010)

It investigates through open-ended questions and 1-7 Likert-type scales well-being and happiness as temporary emotions and as a process of goal setting and meaning-making

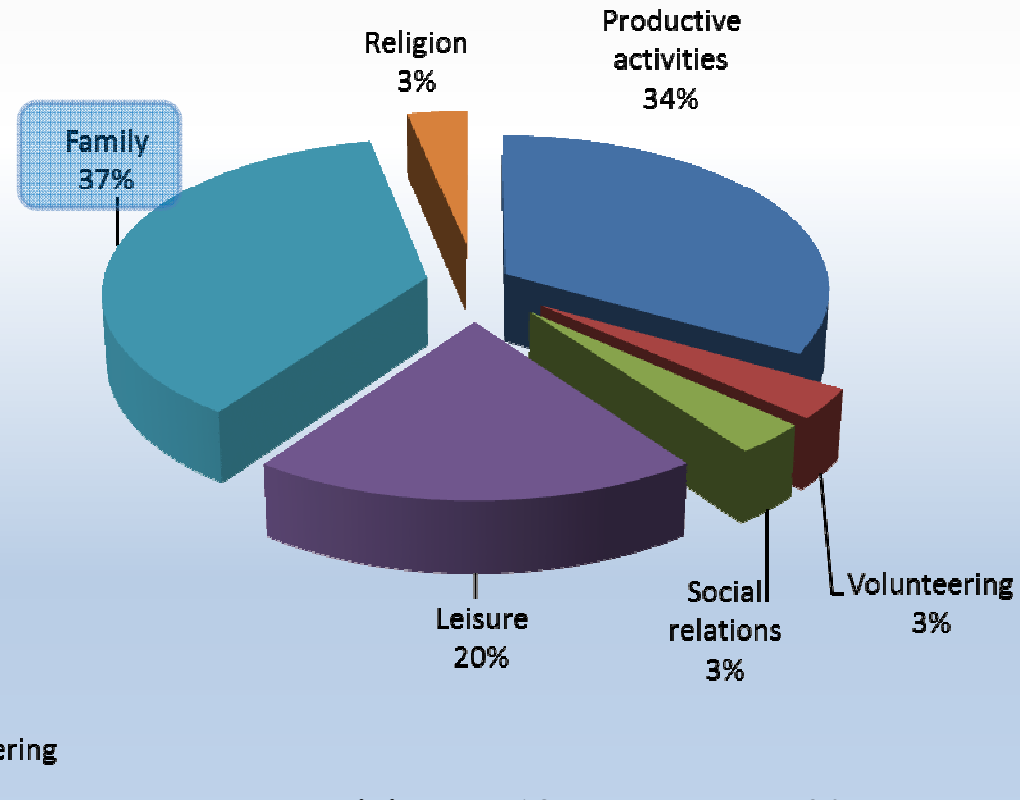
Optimal activities

Patients



N. participants=24; N. answers=47

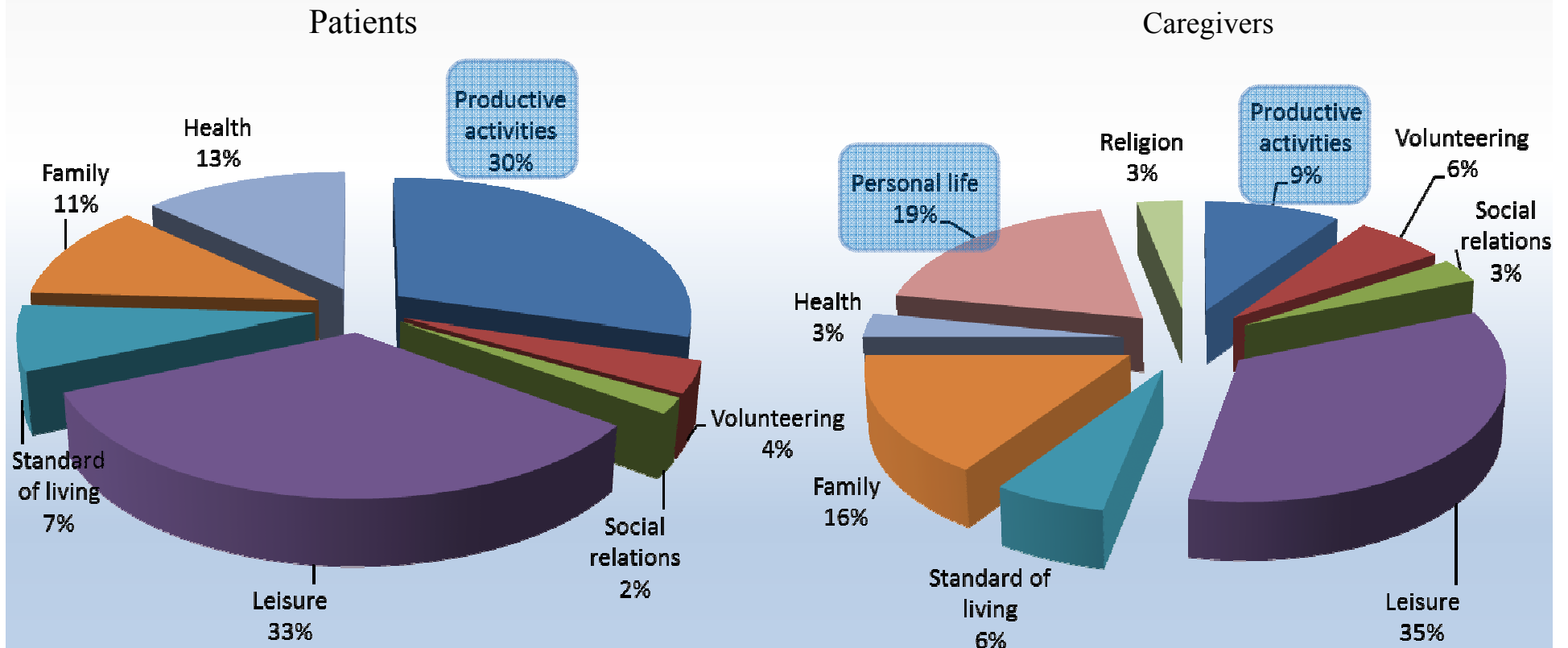
Caregivers



N. participants=18; N. answers=30

A significantly higher percentage of caregivers reported activities with family ($\chi^2=6.59 p<.05$)

Wishes



N. participants=32; N. answers=54

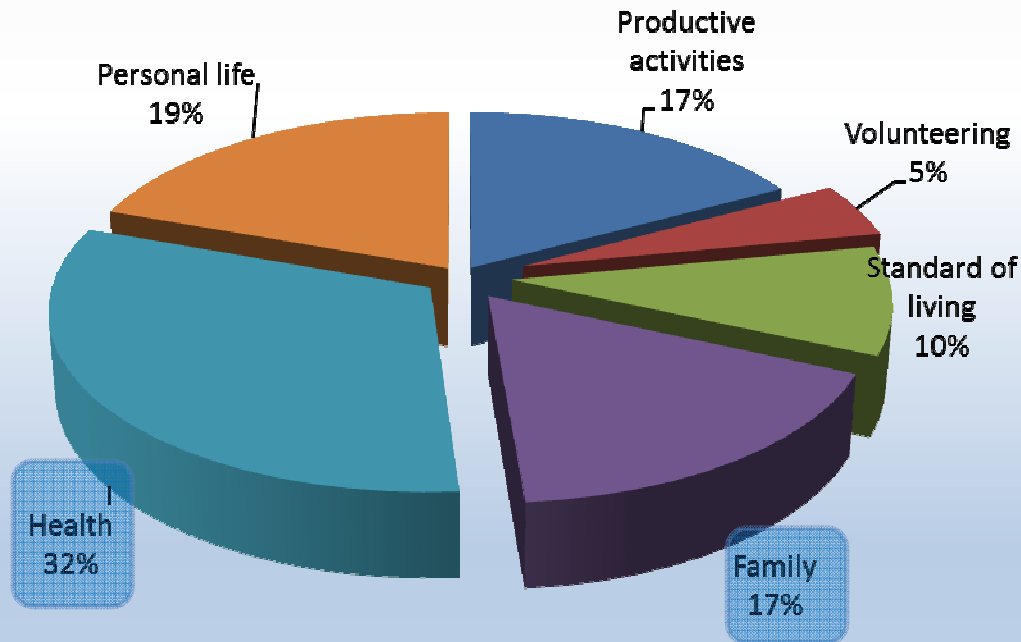
N. participants=21; N. answers=32

A significantly higher percentage of

- patients reported productive activities ($\chi^2=5.10 p<.05$)
- caregivers reported personal life ($\chi^2=10.31 p<.001$)

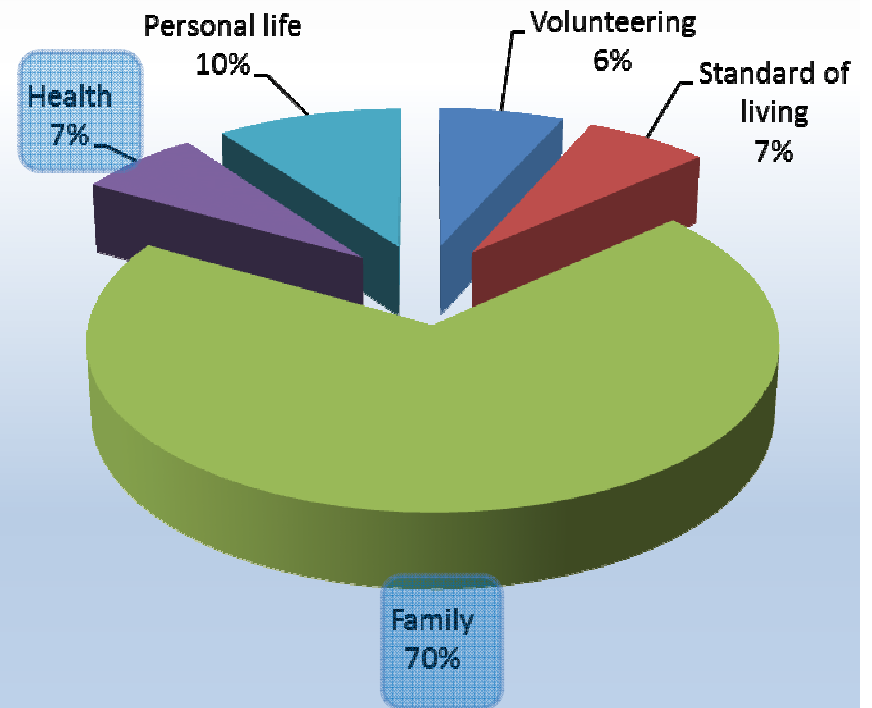
Challenges

Patients



N. participants=32; N. answers=41

Caregivers



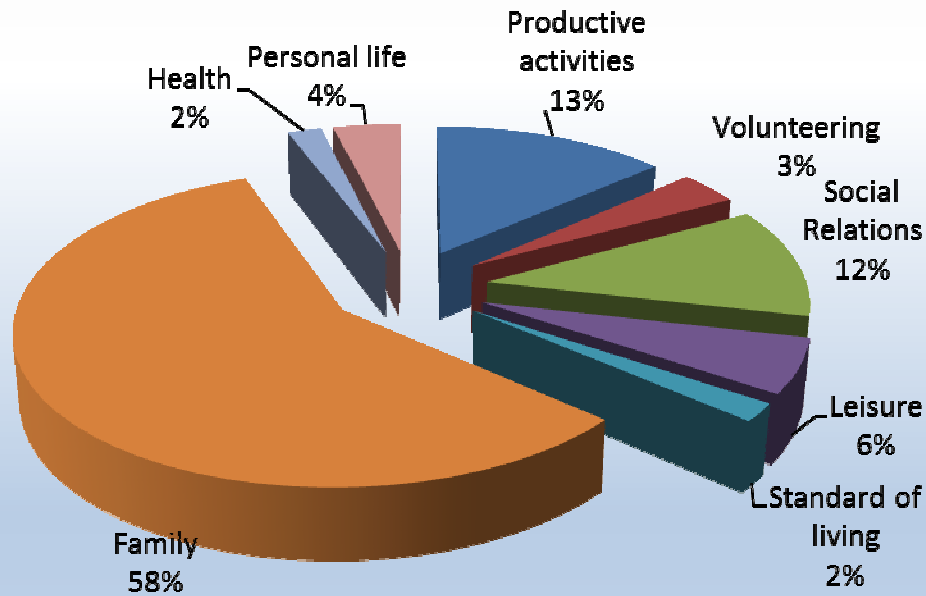
N. participants=21; N. answers=30

A significantly higher percentage of

- patients reported health ($\chi^2=22.28 p<.001$);
- caregivers reported family ($\chi^2=4.23 p<.05$)

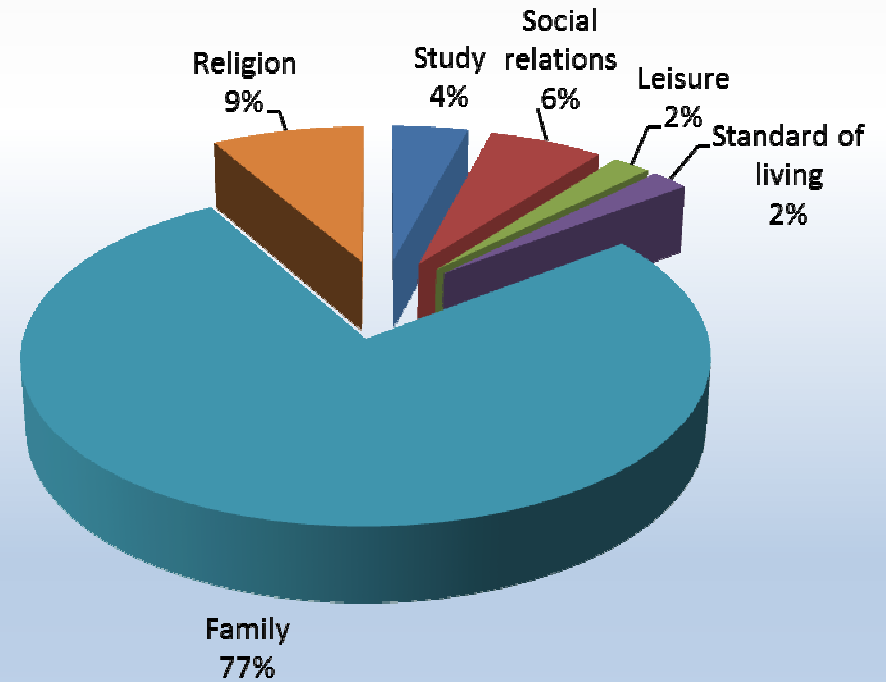
Positive life influences

Patients



N. participants=32; N. answers=52

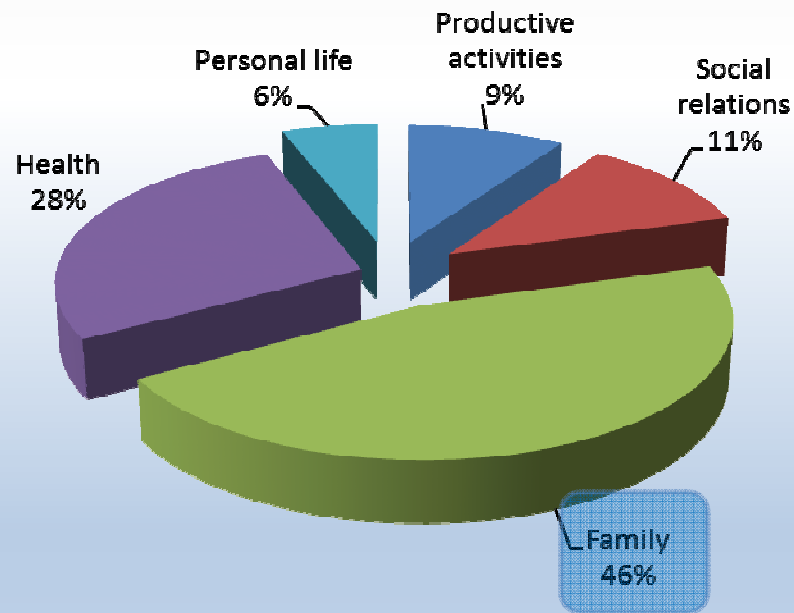
Caregivers



N. participants=21; N. answers=47

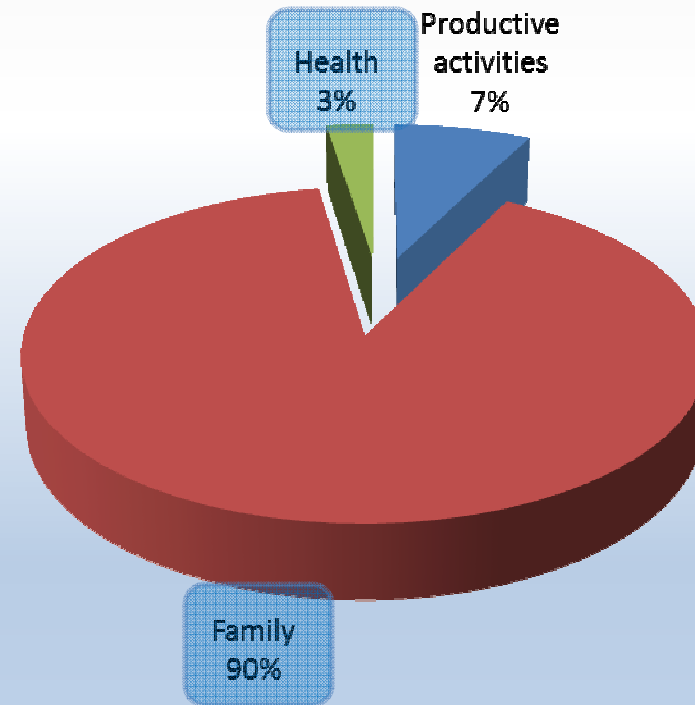
Negative life influences

Patients



N. participants=32; N. answers=40

Caregivers



N. partecipanti=21; N. risposte=40

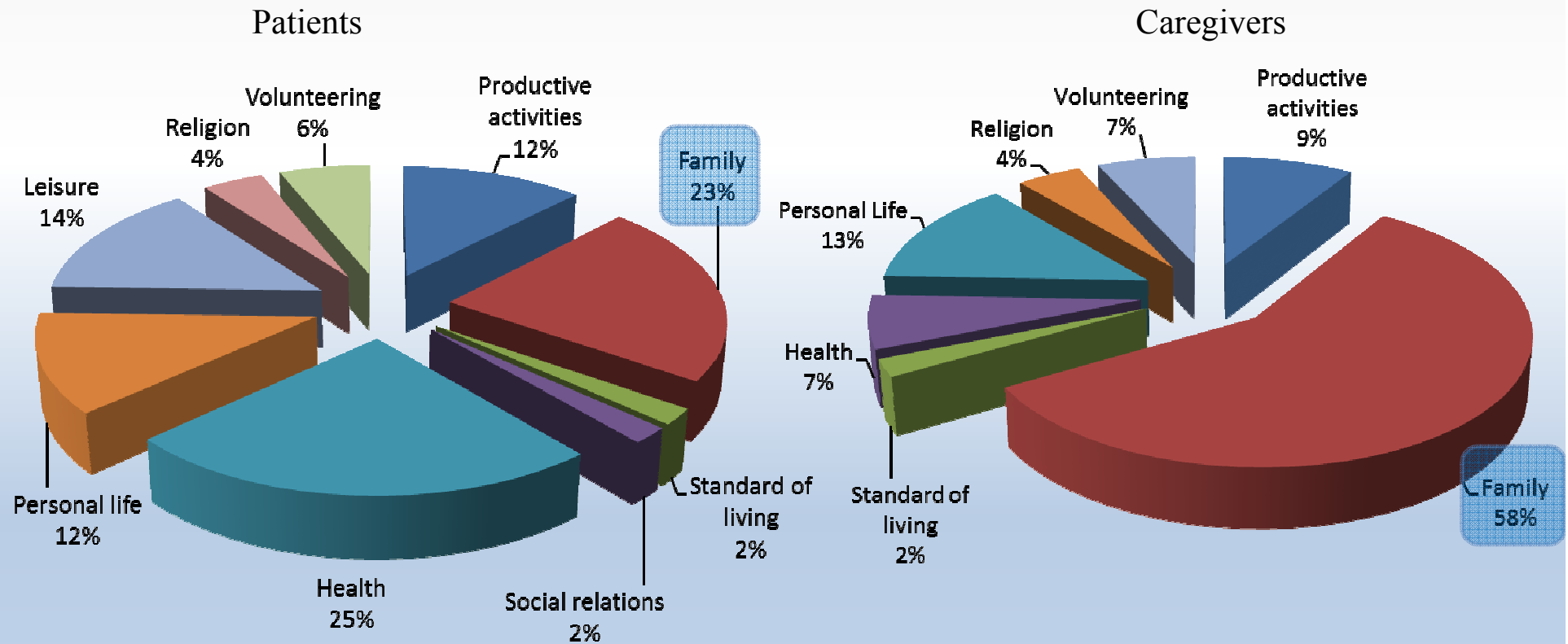
A significantly higher percentage of caregivers reported health ($\chi^2=5.17$ $p<.05$) and family ($\chi^2=8.39$ $p<.01$)

Definitions of Happiness

SITUATIONAL	Patients	Caregivers
	(N=32)	(N=21)
	%	%
Family	47,9	20
Relations	13,1	50
Health	26,1	10
Leisure	8,7	10
Spirituality	-	10
Community/society	4,3	-
Total N. answers	23	10

PSYCHOLOGICAL	Patients	Caregivers
	(N=32)	(N=21)
	%	%
Not obtainable	13,6	22,2
Well-being	18,2	13,9
Meaning	9,1	-
Awareness	4,5	-
Emotions	22,8	16,7
Harmony	4,5	8,3
Optimism	4,5	2,8
Autonomy	4,5	-
Achievement/satisfaction	18,2	8,3
Total N. answers	22	26

Goals



N. participants=32; N. answers=49

N. participants=21; N. answers=48

A significant higher percentage of patients reported leisure ($\chi^2=8.21$ $p<.01$)

Conclusion (1)

Psychological resources: suggestions for patients

At the individual level

- Cultivation of challenging activities
 - physiotherapy training
 - active leisure

At the social level

- Family as a source of support
 - as a context in which individuals can express competencies and share positive experiences

Conclusion (2)

Psychological resources: suggestions for caregivers

At the individual level

Optimal activities in extra-family domains

Opportunities for diversion and relaxation

At the social level

Social relations as a support

as a context in which individuals
can share positive experience

“Se io fossi anima
Leggerei l’anima del prossimo
Se fossi gioia
giocherei con il prossimo
Se fossi morta
Mi odierai
Se fossi fuoco
Mi brucerei le gambe
Ma se fossi vita
Andrei avanti a vivere”

D.M. 2009

“If I were soul
I would read into my neighbour’s soul
If I were Joy
I would play with my neighbour
If I were death
I would hate me
If I were fire
I would burn my legs
But, If I were life
I would go on living”

D.M. 2009

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