



Women with metastatic breast cancer: life, needs, illness

A Europa Donna Italia investigation

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What we investigated...

- ❑ **Experience of the disease and its impact on daily life**
- ❑ **Impact of treatment on daily life** (particularly side effects and what a woman needs to cope with them)
- ❑ **Choice of treatment centre** (influences, difficulties, needs)
- ❑ **Relationship with physician**
- ❑ **Support and assistance needs**
- ❑ **Bone metastases** (experience, impact on daily life, importance of treatment)

Study design

ONLINE BLOG



**EXTENSIVE
QUANTITATIVE
INVESTIGATION**

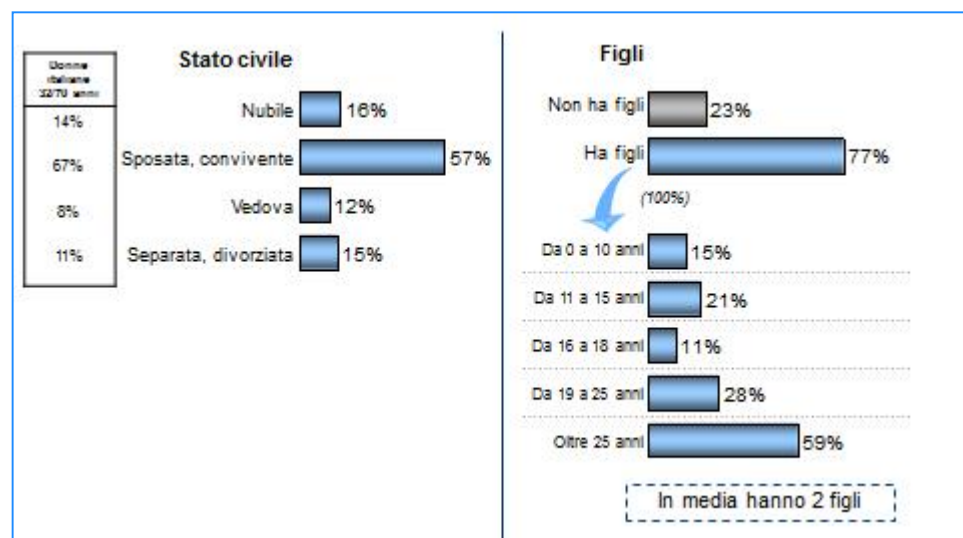
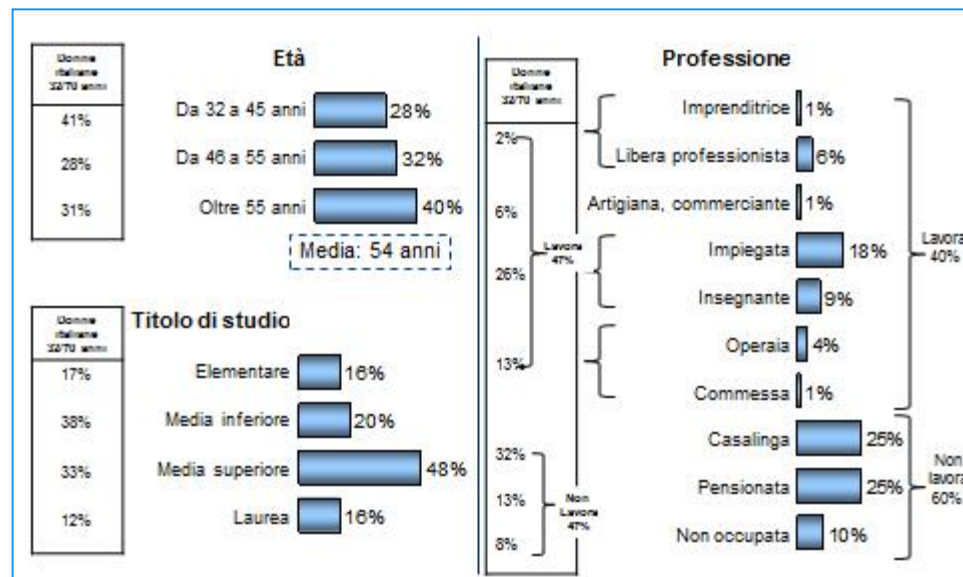
- Community of 15 patients with metastatic breast cancer
- Duration 2 weeks
- ...a sheltered environment where women could exchange views and experiences
- ...where they could talk freely about their hopes, fears and needs

- Structured questionnaire completed by 69 women with Metastatic breast cancer
- .. to investigate and experiences, needs, and expectations

The characteristics of the women

The characteristics of women interviewed

- **YOUNG.** Average age 54 years, almost 30% under 45 years
- **COMMITTED:** with job, family and loved ones
- Central role in family: most married, half have a child under 18 years
- Nearly half have a job (like most Italian women of the same age)



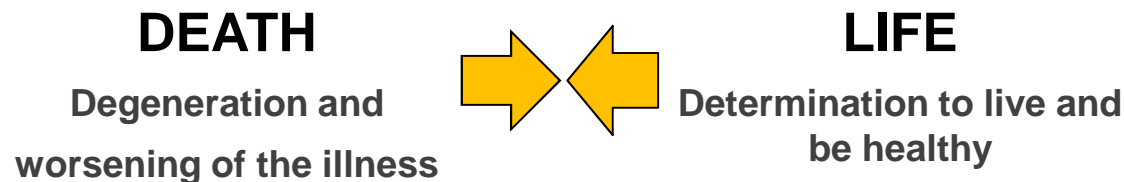
Experience of the illness

Experience of the illness: a monster

“A MONSTER”
“A BEAST”

- Cruel, Unconquerable, Unstoppable
- An Alien Presence, Insidious, Unwanted

... they describe how they are engaged in a **LIFE OR DEATH STRUGGLE**



A struggle in which it is essential to **PLAY AN ACTIVE PART**
... stop being a **PASSIVE VICTIM**
and **TAKE CONTROL** of one's treatment and life

Experience of the illness: patients in their own words

*"... After my initial despondency and uncertainty, I know my true self will reassert itself: **I will struggle against this beast and expel it...**"*

"It is not the first time, although psychologically it's more difficult than before,

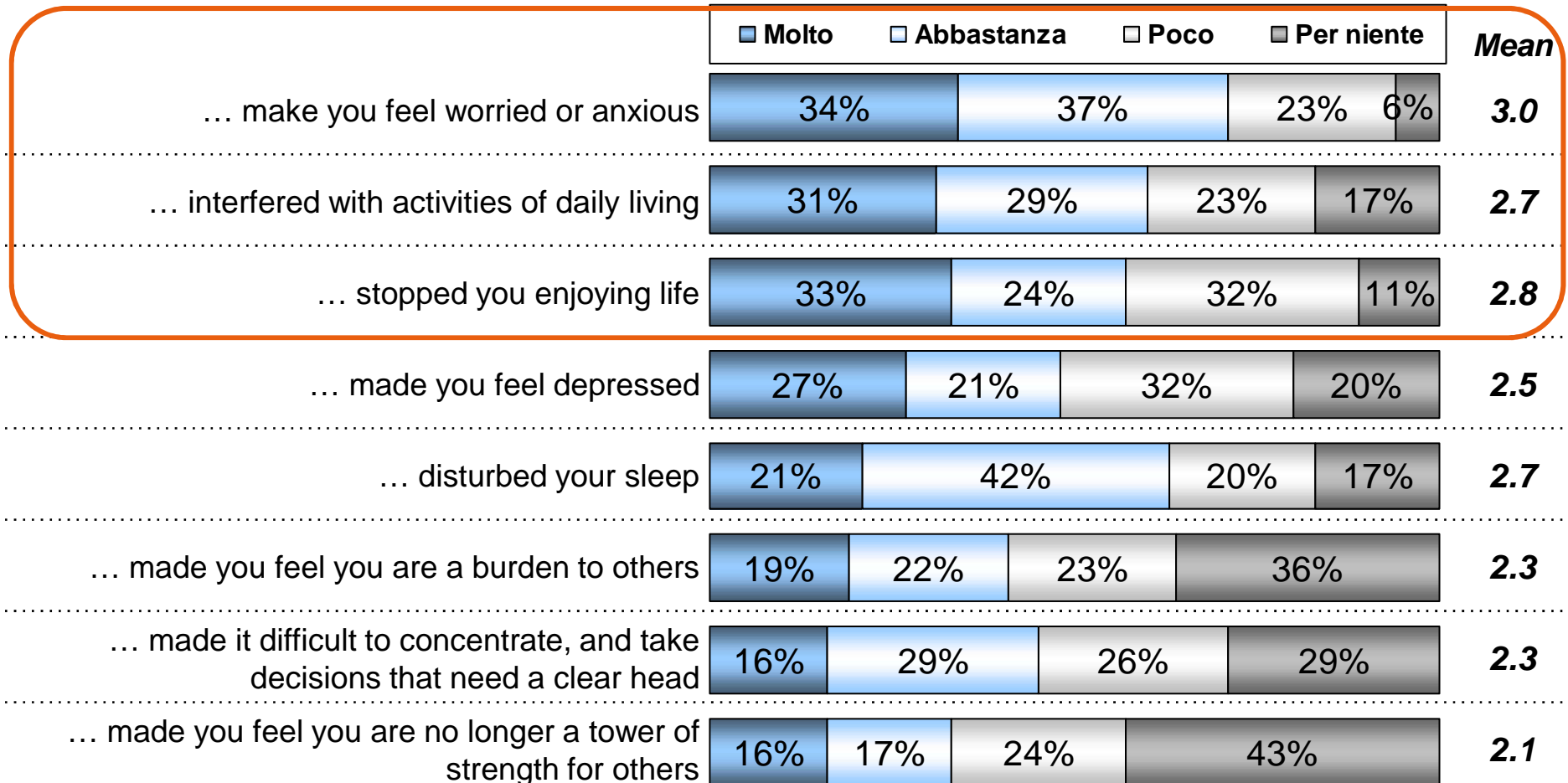
I want to fight this illness, I want to look after myself ..."

My husband said "you yourself are not ill, you simply have a condition"

This thought gives me strength.

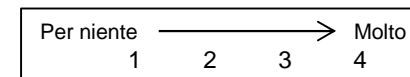
The disease generates anxiety and worry, and disrupts normal life
 ...although most women fight to live their lives to the full

Over the last month to what extent did your disease ...



* Those with a job
 ** Those with husband/partner

Scala di valutazione



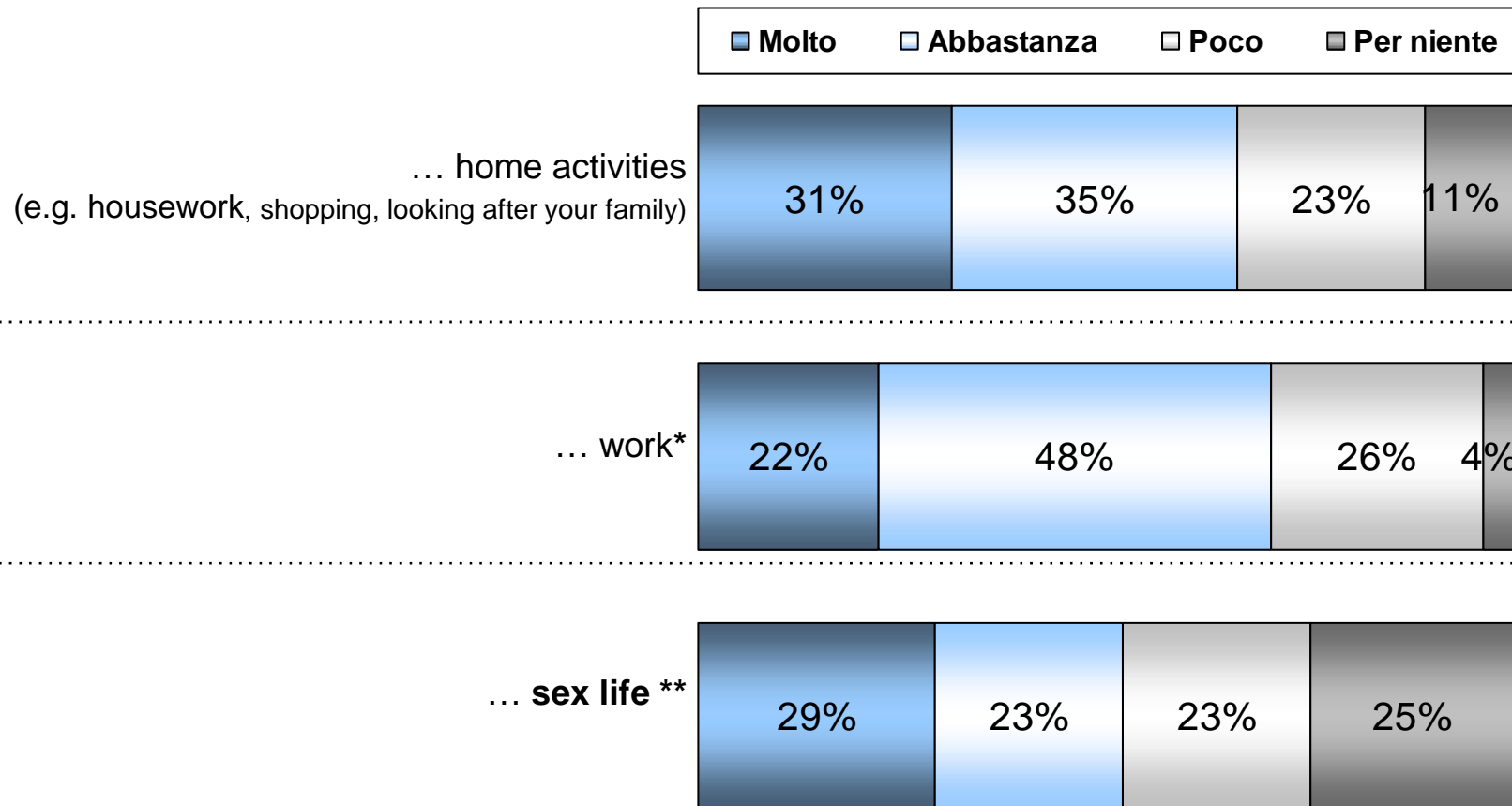
Experience of the illness: patients in their own words

“This morning I woke up feeling as if I had been crushed by tank – pain in my bones everywhere. I walked unsteadily into the bedroom of my two daughters. Their smiles gave me the strength to make breakfast and go to work. How do I experience this disease? It not easy to explain. I have been under treatment for two years: check-ups, scans, endless needles....it has completely changed my life”

“I have been fighting this disease for many years. And just when it seems I’m in the clear, it re-intrudes into my life, without an invitation ... It wants to take over. But I won’t make it easy I am extremely determined. I have willingly submitted to all the treatments, even the most difficult. Just breaking down and giving up doesn’t help anyone”

The disease interferes with work and play, emotional life and sexual life

To what extent does your disease interfere with..

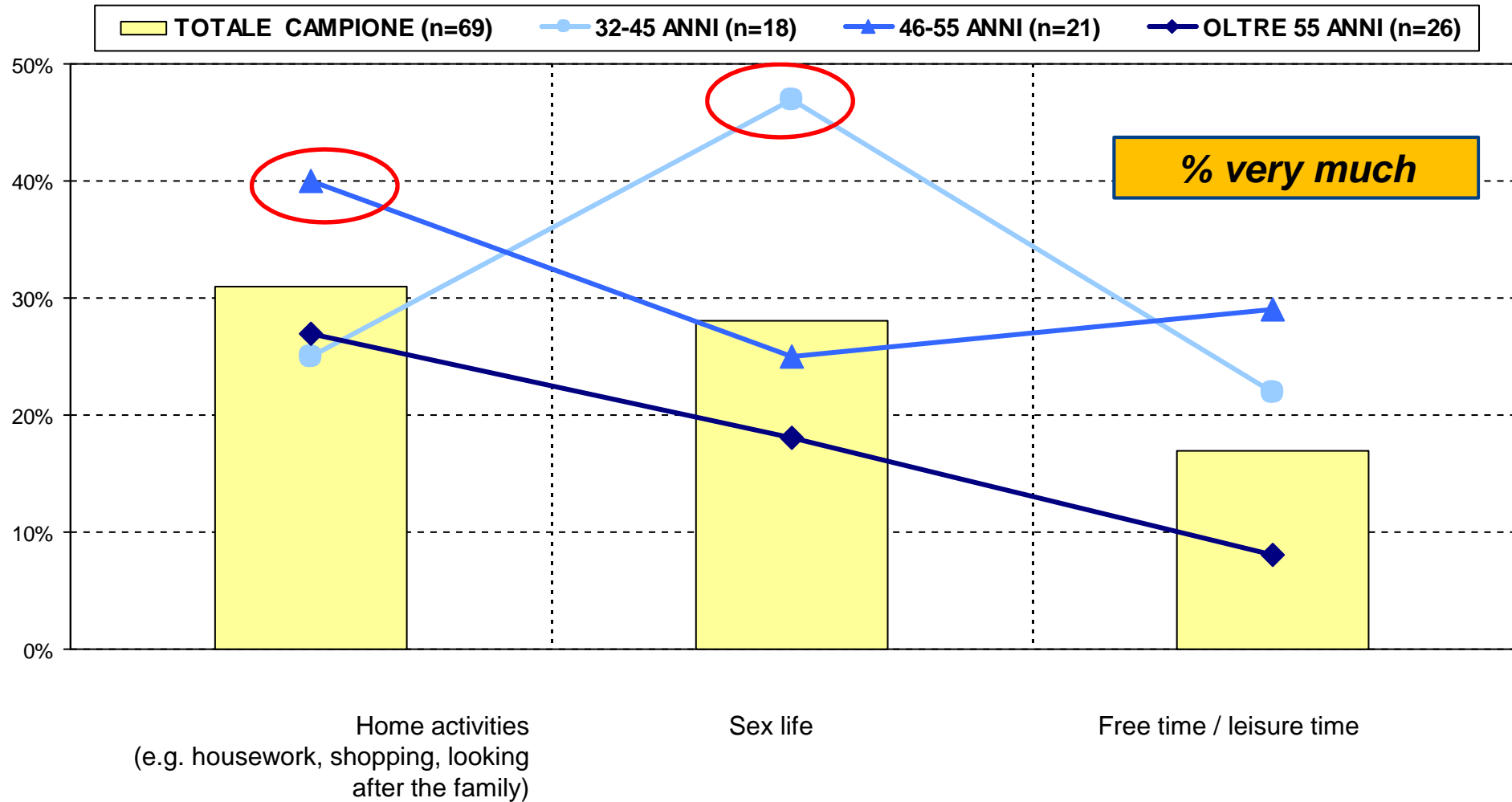


* Those who go out to work

** Those with a partner

Impact on emotional and sexual life is greater for young women

To what extent does your disease interfere with..



Experience of the illness: patients in their own words

“It’s also difficult for my husband: I’m not the woman I was before treatment. The treatment has changed my moods, my desires, my sexuality... I no longer feel as I once did toward my husband”

Treatments

It emerged that women are highly ambivalent about their treatments

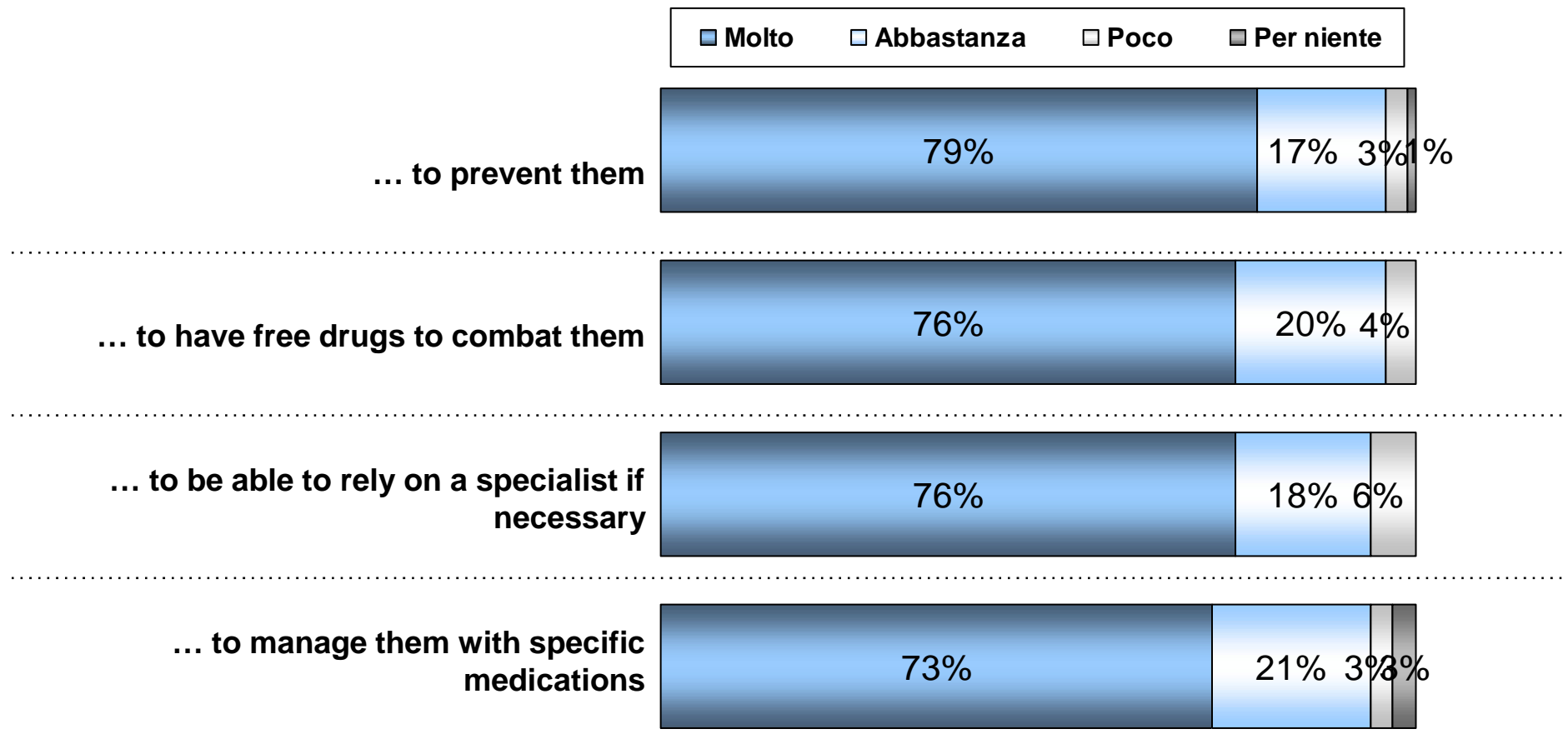
“One the one hand it’s an ally, that helps you fight the disease ...

...on the other hand it poisons your body.. the side effects are really awful, and you have to convince yourself you need the treatment ...

... deep down it repels you, you want to stop it, get away from it, forget it”

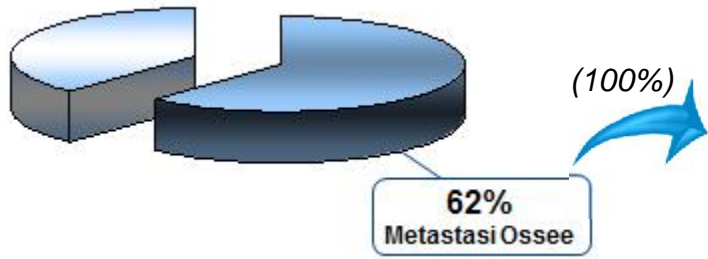
It emerged that women want help to support the side effects of their treatments. They want to be able to prevent or reduce them, with free medication and free access to specialist doctors

With regard to treatment side effects, to what extent is it important for you....



Bone metastases

It emerged that bone metastases have a strong emotional impact



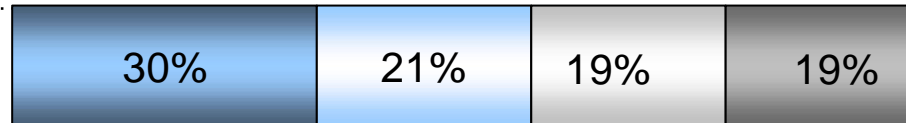
To what extent do bone metastases...



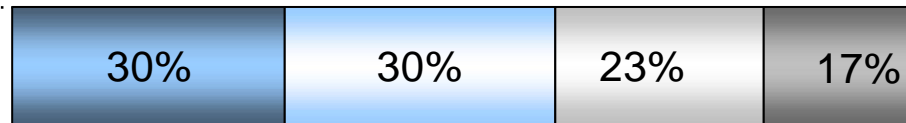
... make you feel worried



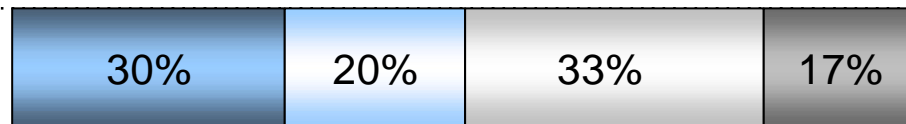
... make you feel depressed



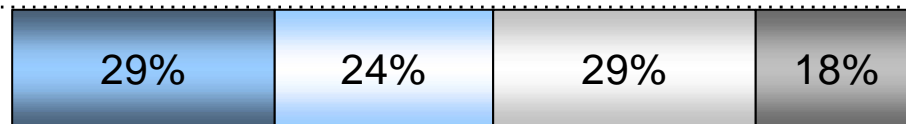
... impede your normal daily activities



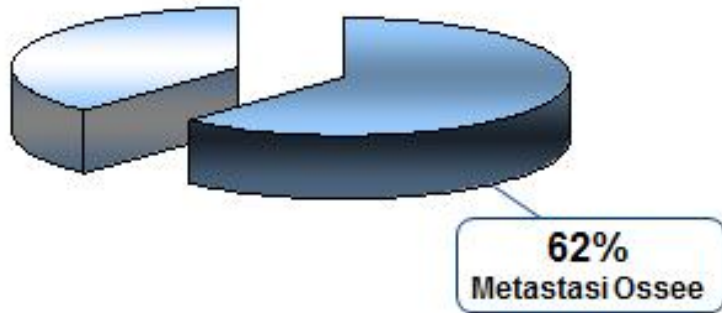
... disturb your sleep



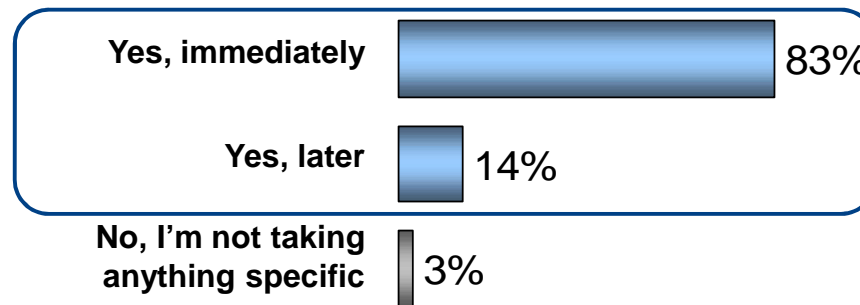
... stop you enjoying life



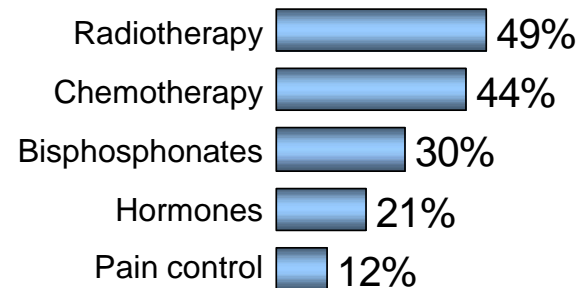
Signe and symptoms leading to the diagnosis of bone metastases (Patients with bone metastases, n=43)



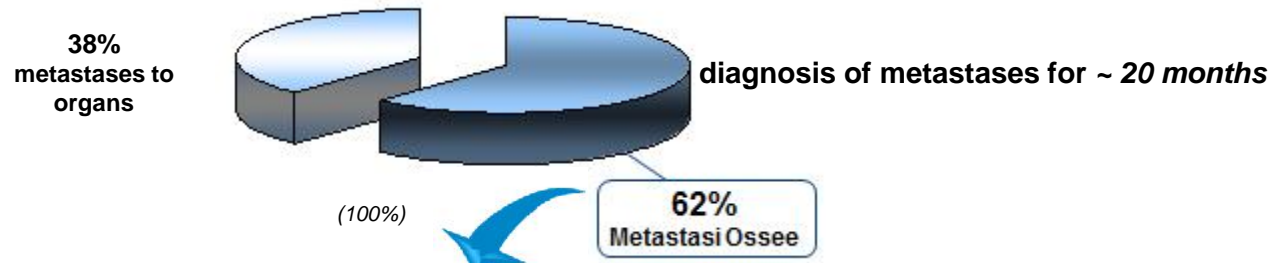
When bone metastases were diagnosed, did your doctor suggest specific treatment?



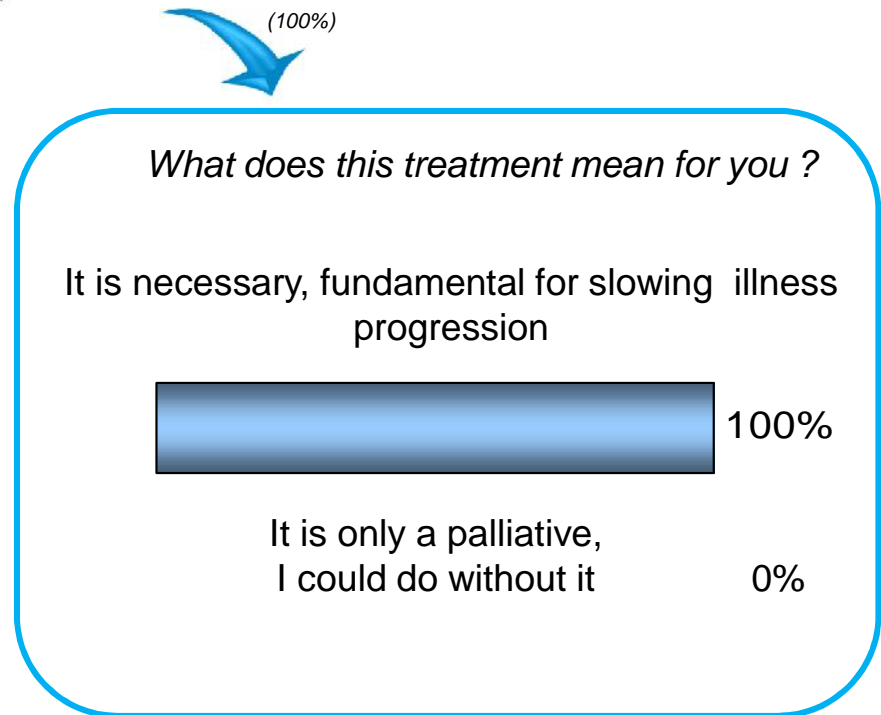
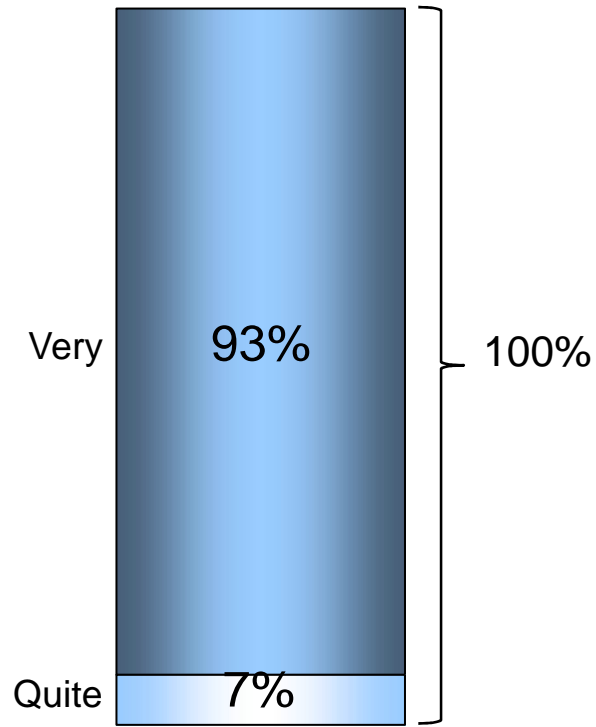
What treatment for bone metastases were your prescribed?



It emerged that specific treatment for bone metastases is essential: gives hope that the disease can be stopped

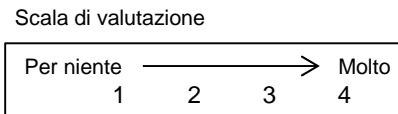


How important is it for you to have a specific treatment for bone metastases?



Little / not at all

Mean 3.9%



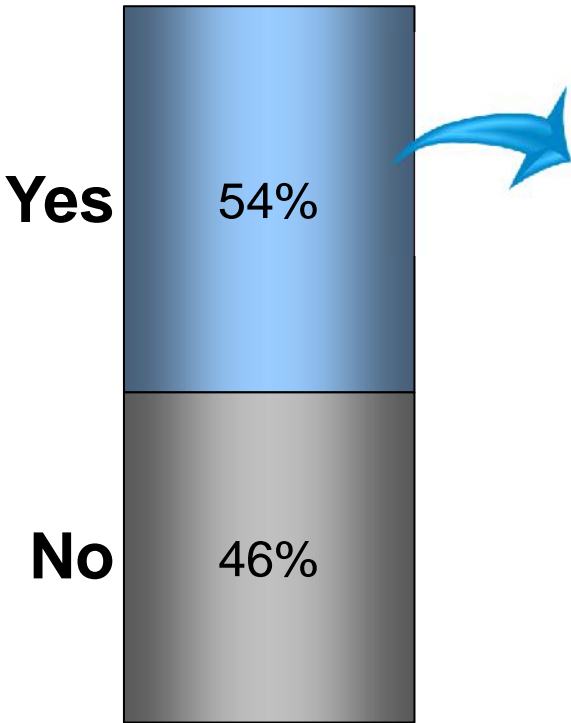
Importance and significance of specific treatment for metastases:
patients in their own words

***“When I learnt I had metastases I was in despair,
I lost hope...
But when the doctor told they could be
controlled, that treatments could be effective,
I started fighting again.”***

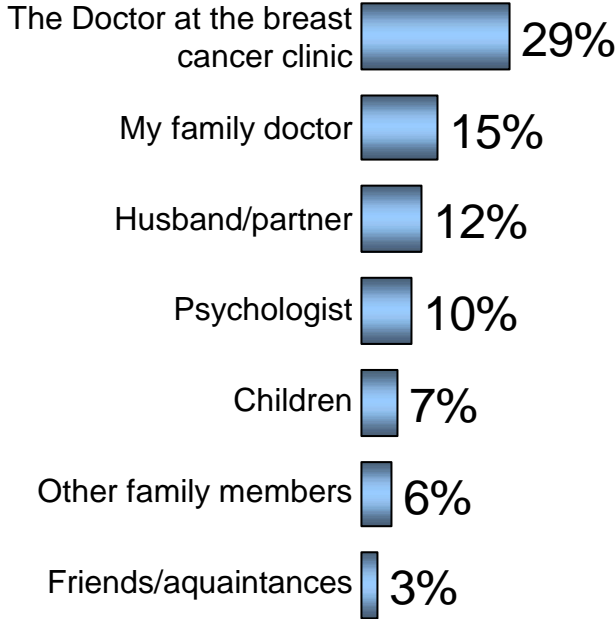
Needs

Over half the women said they needed more support, especially from the doctor

Do you feel the need for more support and attention?

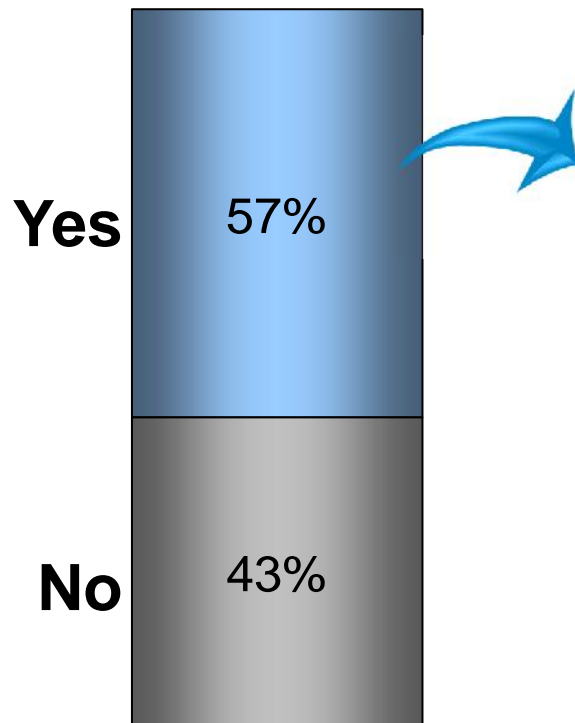


Who do you wish would support you more?

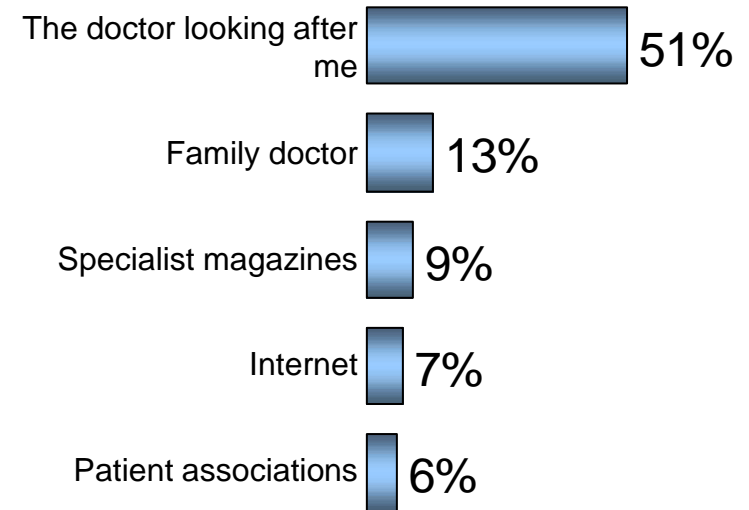


2/3rds of the women felt the need for more information about the disease and its treatment.... particularly from the doctor

Do you feel the need for more information about the disease and its treatment?

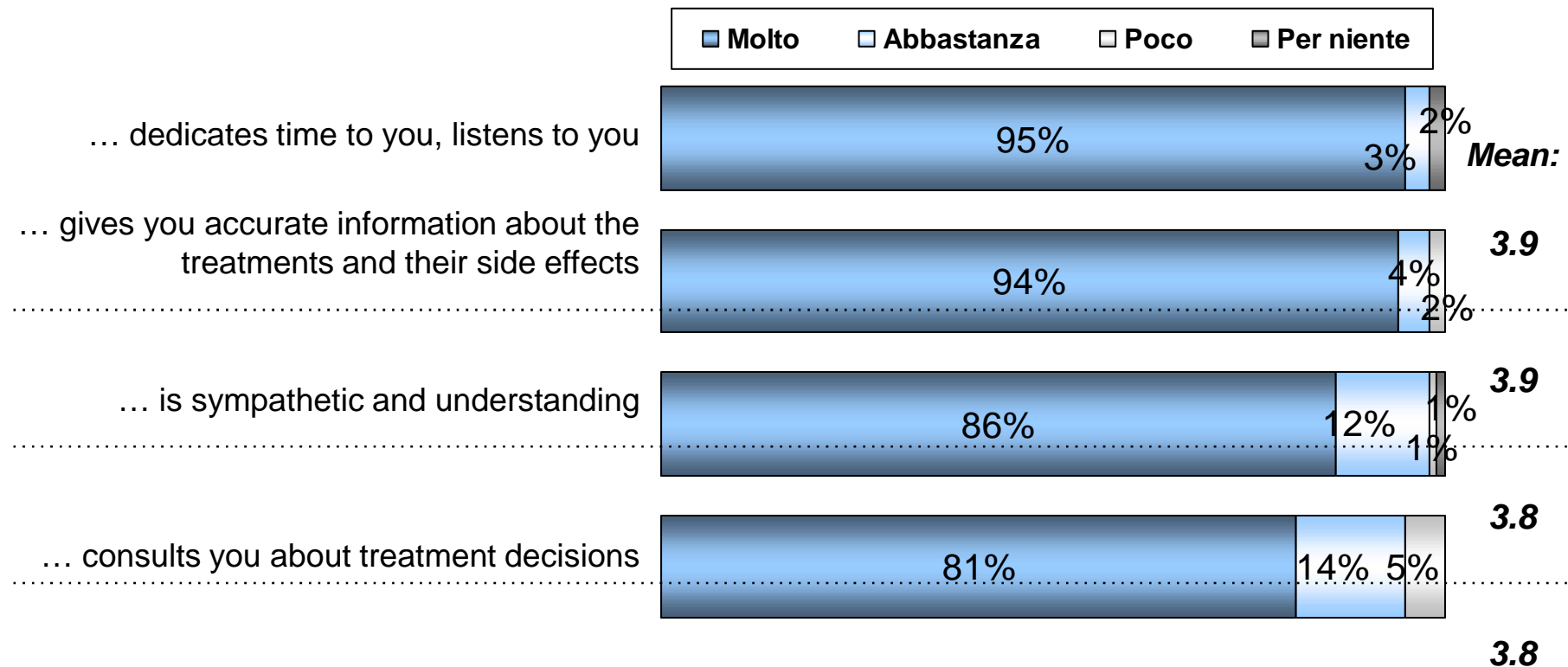


Who do you wish would give you more information ?

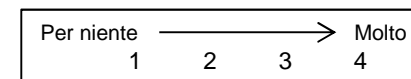


Fundamentally, the patient wants the doctor to listen to her, to be sympathetic, to give information ... the patient also to be involved in decisions about her treatment

How important is it for you that your doctor...



Scala di valutazione



Support: What's required and what needs to be improved:
patients in their own words

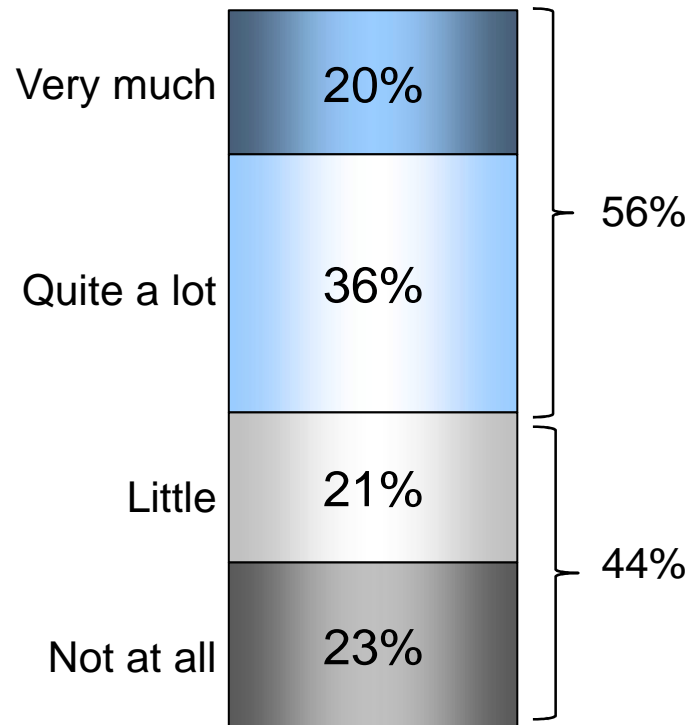
*“I think a hospital has a duty to inform patients of their rights particularly about invalidity payments and travelling expenses. But they tell us nothing. It is the patients who inform each other: when I see another patient looking lost I ask if they want help and offer information. **Some doctors are irritated when asked for certificates, they say they don't have time, that I should wait till next time ...**”*

“New and perhaps better treatments are often given only if you are in a clinical trial. But patients don't know where these trials are conducted or how to get enrolled. Often the treating doctor gives no information, for fear of losing the patient if the trial is being conducted at another center”

Patients' rights

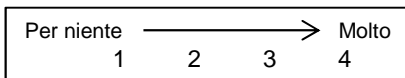
Patients fear losing the right to healthcare. Their greatest fear is losing their entitlement to treatment

In the current economic climate in Italy, do you fear that your right to health care may be jeopardized?

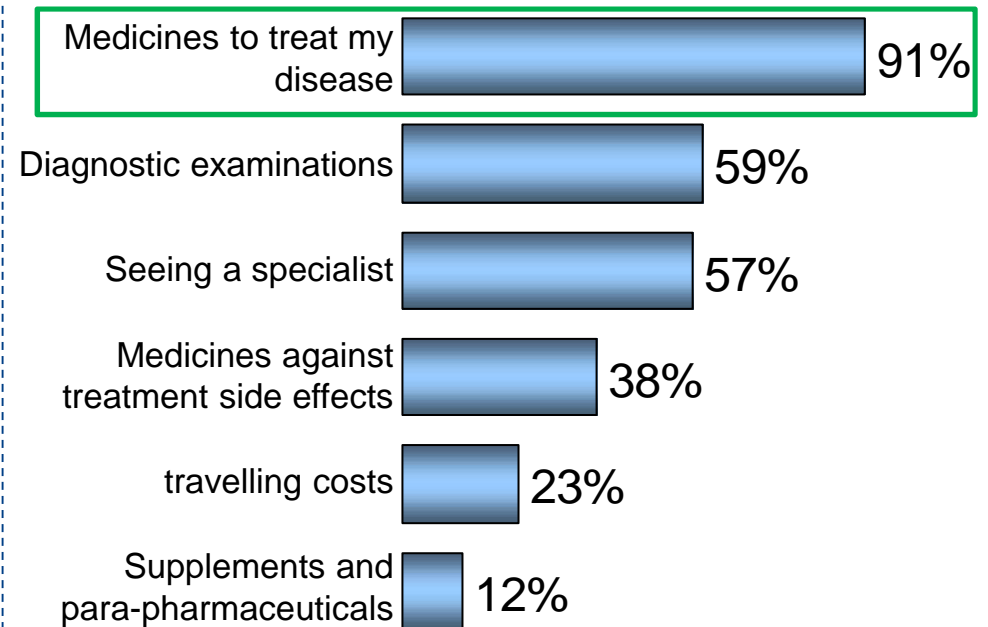


Mean 2.5

Scala di valutazione



If health spending were cut, what cuts or increased costs would cause you most difficulties?



Fears about the right to healthcare in the future: patients in their own words

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to rights by such penny-pinching. Cancer patients need prompt treatment. They should have the right to any treatment that may help them.”

Fears about the right to healthcare in the future: patients in their own words

“With regard to new treatments: too much time passes before they become available to patients Time for approval in Italy is from 6 months to 2 years, according to Region. This is a negation of the right to healthcare, which should be sacrosanct”

Summary of main findings

Characteristics of the women interviewed

- Mean age 54 years, almost 30% under 45 years
- Most are married, half have a child under 18 years
- Nearly half have a job outside the home

Living with metastatic breast cancer

- Metastatic breast cancer was perceived as a **LIFE AND DEATH STRUGGLE**
 - ... A struggle in which women tried to take control of their own destinies
- The disease created worry and anxiety, totally disrupting women's lives
 -although most fought to live their lives to the full
- The disease disrupted activities of daily living, work, affective life, and sexual life
- The disruption of sexual life was felt most acutely by young women: the disease forced them to redefine their femininity and their sexual identity

Treatments

The women were strongly ambivalent about their treatments

- On the one hand it was an ally... helping them fight the disease.
- On the other it was a poison...
- The side effects were considered “really awful”, women had to convince themselves they needed the treatments ...but deep down they wanted stop them, get away from them
 - Treatment side effects affected young women the most: drastically disrupting their emotional and sexual lives
- The women strongly felt the need for help to combat the side effects of treatments with free medicines and access to specialists
- They wanted specific treatments for bone metastases to maintain hope that illness progression could be slowed

Needs

- Over half the women felt the need for more support and sympathy from the doctor
 - Two thirds felt the need for more information about their disease and its treatment... especially from the doctor
- Less red tape, with rapid access to examinations and their results, was also considered fundamental
- Not only did women want a sympathetic and listening doctor, they also wanted to be involved in decisions about their treatment

Fears about the right to healthcare in the future

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to right by such penny-pinching. Cancer patients need prompt treatments. They should have the right to any treatment that may help them.”

The right to healthcare

Strong fear that the right to healthcare could be revoked

Strongest fear that the right to treatment could be revoked

“It is totally unjust that anti-cancer treatments can be denied to people who might benefit from them, simply to reduce costs. The finances of the state will never be put to right by such penny-pinching. Cancer patients need prompt treatments. They should have the right to any treatment that may help them.”

*“The government has instituted this ‘super-ticket’ for cancer drugs, so that letrozole for example costs 7 euro. This is not a high price but some can’t afford it. And it is a disgrace. In all parts of Italy – even the richest Regions – we have to pay for breast cancer drugs. **A civilized country should not seek to save money by making cancer patients pay for their treatments. These drugs are matters of life or death for cancer patients**”*