



Prostate Cancer: Living, not Just Surviving

Results of a pan-European survey of prostate cancer patients, caregivers and healthcare professionals.

Contents

Foreword	3
Executive Summary	5
Prostate Cancer: Living, not Just Surviving Survey - Key Findings:	
01. Impact of Prostate Cancer on Quality of Life	7
02. Communication between Patients, Caregivers and Healthcare Professionals	13
03. Role of Family Members in Supporting Patients with Prostate Cancer	17
04. Support for Patients and Caregivers on Addressing the Quality of Life Impact of Prostate Cancer	21
Conclusion	23
About the Prostate Cancer: Living, not Just Surviving Survey	24
References	25

Foreword

Latest figures show that there are currently three million men living with prostate cancer in Europe.¹ The number of new prostate cancer cases per year has increased by over 150% between 1999 and 2012 – and continues to rise.^{2,3}

Many factors can be attributed to this increase in prostate cancer incidence, including the aging population, as well as improved diagnostic methods and public awareness leading to prostate cancers being identified at a much earlier stage.

More extensive research into cancers has also led to improvements in treatment, so men are surviving for longer with the disease – almost 1.5 million men in Europe have now been living with prostate cancer for five years or more.⁴

As a result of this shift, prostate cancer is increasingly considered to be a chronic illness. Of course, this opens up a new challenge to healthcare professionals, like me, to start looking for a more holistic approach to managing this disease.



Professor Louis Denis
Onco-Urologist and Strategic Consultant,
Europa Uomo

The **Prostate Cancer: Living, not Just Surviving** survey aims to shed light on the perspectives of patients, caregivers and healthcare professionals to help us understand the day-to-day impact of prostate cancer and how we can improve the way we address the physical, emotional and social problems associated with the disease.

By examining prostate cancer in this way, we aim to better recognise how to improve public understanding of prostate cancer and the impact that it has on the everyday lives of patients and the people they love.

We hope that by highlighting these unmet needs, this report will inspire a change in treatment management across Europe.

A handwritten signature in black ink that reads "Louis J. Denis".

Professor Louis Denis



Executive Summary

Prostate cancer is the most commonly diagnosed cancer in men, with almost 400,000 new cases diagnosed in Europe per year.¹ The physical impact of the disease can have a negative impact on a patient's everyday life, which can in turn influence their emotional well-being and relationships with their partners and family.

The **Prostate Cancer: Living, not Just Surviving** report delves deeper into the personal experience of prostate cancer and examines insights from men across Europe living with this disease, as well as caregivers and healthcare professionals.

Prostate cancer is reported to restrict the everyday life of patients, with 80% of patients feeling that they are unable to do activities they used to enjoy before their diagnosis (85% report that they are unable to be intimate with their partner following diagnosis).

In addition, the survey reveals that prostate cancer patients are more likely to worry about intimacy problems (54%) and feeling ill (41%), than the risk of death from the cancer (36%). 66% of patients who experience a negative physical impact as a result of their disease link this to tiredness and fatigue, more than disability (41%) and pain (22%).

A key trend, noted in the results, suggests that communication between patients, caregivers and healthcare professionals needs to be improved. As an example, 62% of prostate cancer patients are not willing to talk about intimacy problems with their partners.

According to the survey results, almost all (96%) healthcare professionals believe that the role of family in supporting the patient is important. 39% of patients report that their partner is the family member most negatively impacted by their disease, compared to their friends (9%) and their children (7%).

The survey found that only 14% of healthcare professionals reported feeling sufficiently equipped with the adequate resources to address patients' quality of life issues.

This survey suggests that more needs to be done to raise awareness of the tools available which can help to address the emotional and physical needs of prostate cancer patients from a healthcare professional, patient and caregiver perspective.



Prostate Cancer: Living, not Just Surviving Survey - Key Findings:

The **Prostate Cancer: Living, not Just Surviving** survey results provide a comparative look at the perspectives of patients, caregivers and healthcare professionals on the impact of prostate cancer. The results of the survey reveal the following:

01. Impact of Prostate Cancer on Quality of Life

Prostate cancer patients perceive the **emotional impact** of their disease (**46%**) as equally negative as the **physical impact** of the disease (**46%**).

Restrictions on everyday life

Prostate cancer can restrict the everyday life of patients and their caregivers. Patients report that the **negative physical impact** of the disease can cause an **inability to participate in simple activities** that they were able to do before their diagnosis. This can have a harmful emotional effect on themselves and those who care for them.

Almost **80%** of prostate cancer patients feel that they are **unable to do activities** they used to enjoy before their diagnosis.

Tiredness and fatigue

Tiredness and fatigue are reported to be a major problem for prostate cancer patients, particularly for those on medications (83%) or in men where the cancer has spread to other parts of the body (93%). 66% of patients who experience a negative physical impact as a result of their disease say that this is linked to tiredness and fatigue.

Those on **medication (31%)** or in the **metastatic phase of their disease (42%)** are also more likely to report that they find it **hard to accept the physical and emotional impact of their prostate cancer**.

Tiredness and fatigue are most likely to be linked to the negative physical impact experienced by prostate cancer patients, over disability and pain.

Figure 1.1
Factors that cause the **negative physical impact** associated with prostate cancer:

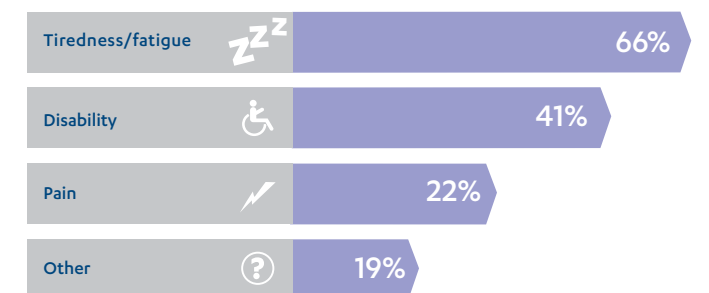
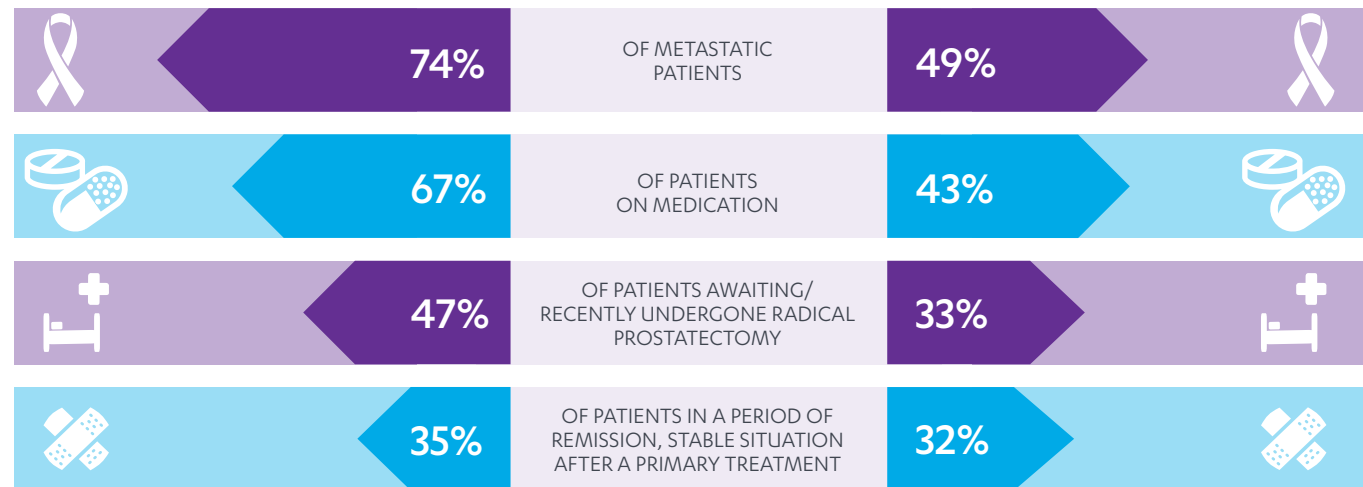


Figure 1.2

The **emotional and physical functioning** of prostate cancer patients at different stages of their disease:

Patients who are unhappy with the way they are functioning **physically**:



Patients who are unhappy with the way they are functioning **emotionally**:

“The most overriding feature is fatigue, which is something you have to get your head around and learn to live with.”

Hugh Gunn,
Patient and Tackle Prostate Cancer Trustee, UK.



Exercise

Survey findings indicate that having the **energy to keep fit** and carry out everyday activities is considered important in helping patients to **deal emotionally with their disease**.

Figure 1.3

Impact of **exercise** on prostate cancer patients’ **emotional wellbeing**:



“I’ve been able to keep exercising, and I have to say that this has helped me a great deal with accepting this disease.”

Koos van der Veen, Patient, The Netherlands.

Intimacy

Across Europe, intimacy is shown to be the activity most significantly restricted by prostate cancer.

Figure 1.4

Activities restricted by prostate cancer for patients:

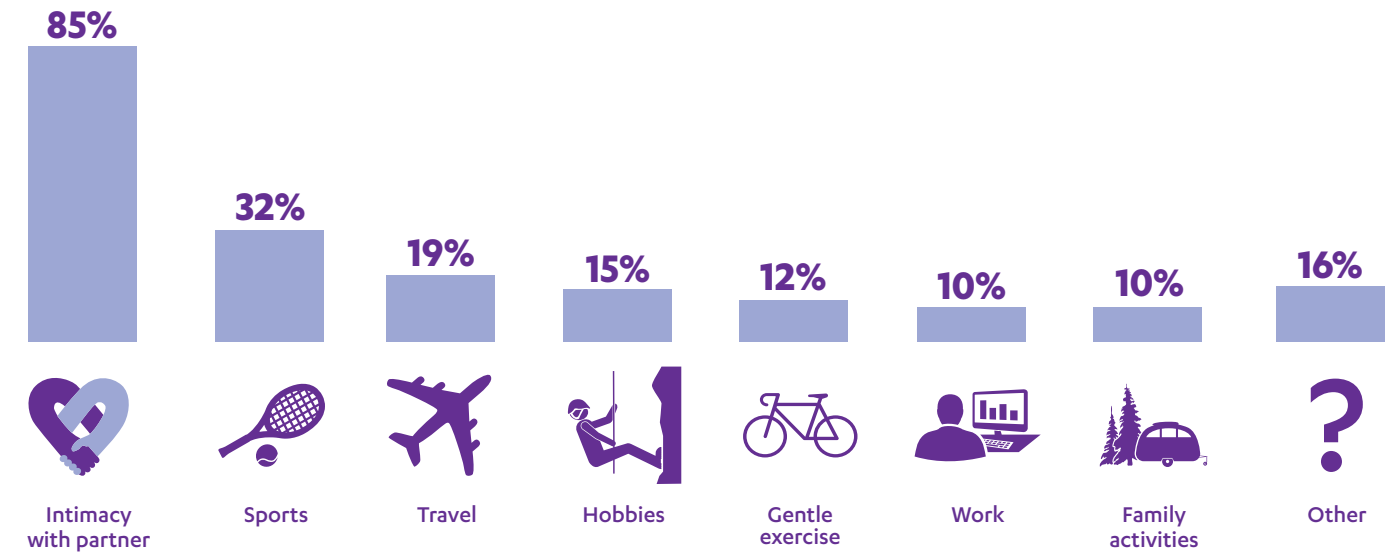
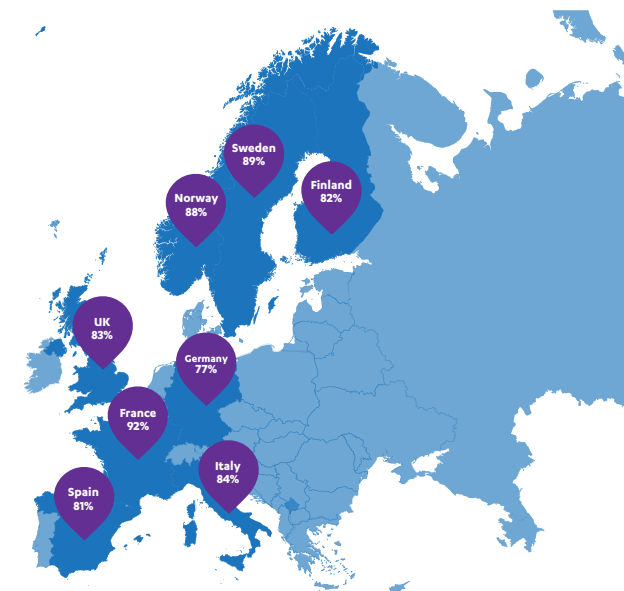


Figure 1.5

Patients across Europe that report **intimacy** to be restricted by their disease:



“It’s the ‘manly’ thing to be continent and potent and both those things usually go.”

David Smith, Patient and former Honorary Secretary of Tackle Prostate Cancer, UK.

In contrast, **34% of caregivers** report that their own **hobbies** and personal activities are **most affected by the patient’s disease**, over their job (32%) and taking time for themselves (20%).

“When my husband was first diagnosed with cancer, I had no idea of the impact the disease would have on his quality of life over the coming years. We were no longer able to pursue our love of the great outdoors. As a previously energetic couple, his fatigue and loss of energy was frustrating and sad for us both.”

Linda Smith, Caregiver, UK.

Worries of patients and caregivers

When reporting about their biggest worries, **patients rank the risk of death second to the impact on quality of life**, such as their inability to be intimate with their partners or feeling ill. However, **83% of healthcare professionals report that they think the patient's biggest worry is death**. Caregivers also report that their priorities are focused on the longer-term survival of the patient rather than addressing the patient's immediate quality of life concerns.

Figure 1.6

Worries associated with prostate cancer patients:



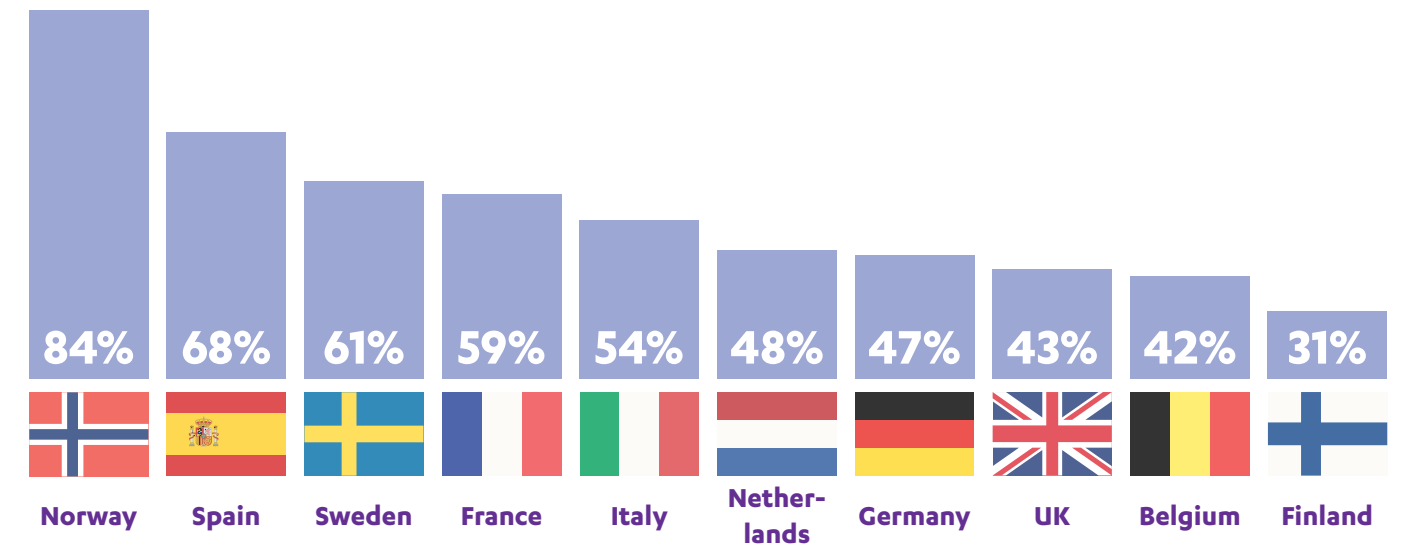
	Patients' worries (reported by the patient)	Patients' worries (reported by the healthcare professional)	Caregivers' worries (reported by the caregiver)
Effect on intimacy with their partner	54%	24%	10%
Feeling ill	41%	67%	57%
Death	36%	83%	59%
Emotional impact on the family	35%	59%	48%
Practical impact on daily family routine	32%	43%	33%
Risk of inheritance of prostate cancer by offspring	28%	10%	27%
Family finances	13%	12%	8%
Other	6%	1%	5%

“Patients may not be revealing their true worries about intimacy problems to their doctors. When we provide a prostate cancer diagnosis to a patient, he often displays worries about how his cancer will threaten his life rather than how it will limit his ability to be intimate with his partner.”

Professor Axel Merseburger, Onco-Urologist, Germany.

Figure 1.7

Patients across Europe who report that they are most worried about the impact of prostate cancer on **intimacy**:



“Prostate cancer is a slow progressing disease and death is often not an immediate threat. Nowadays our educated patients are much more interested in quality of life than in survival. The things that they fear most are the side effects, not only of the disease, but also the treatment. We need to open up with patients so they have a chance to vent their frustrations, anxieties and troubles.”

Professor Louis Denis, Onco-Urologist and Strategic Consultant, Europa Uomo.



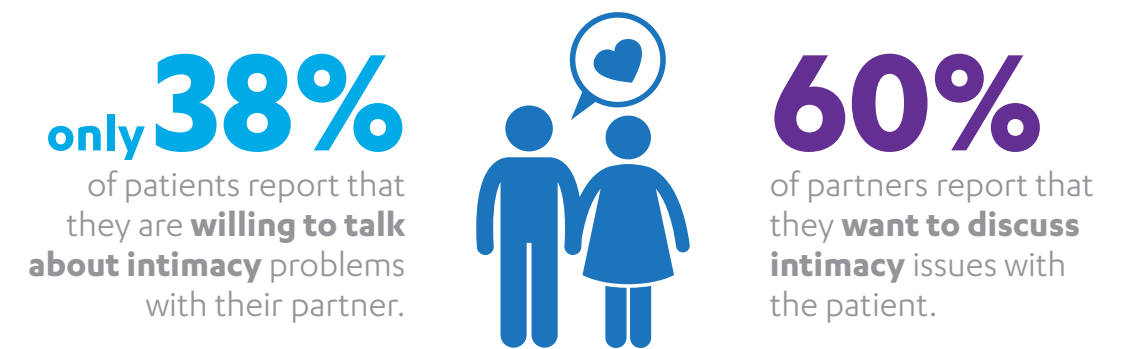


02. Communication between Patients, Caregivers and Healthcare Professionals

Communication barriers

Although the majority of patients say that they are most worried about intimacy problems associated with their disease, they are **not willing to talk** about these problems with their partners.

Figure 2.1
Discussing intimacy problems related to prostate cancer:



“Men with prostate cancer don’t like to discuss intimacy problems with their wives because they try to avoid upsetting them or causing emotional issues when they think they can manage the problem themselves.”

Professor Louis Denis, Onco-Urologist and Strategic Consultant, Europa Uomo.

“Intimacy was a difficult worry for me to discuss with my husband. We gradually accepted that our loving relationship would survive without the ability to be intimate.”

Linda Smith, Caregiver, UK.

“We often see men struggling emotionally with the impact of their disease but they are too embarrassed to discuss their problems with a healthcare professional or even their partner. Communication is vital in avoiding relationship breakdown between patients and their partners at a time that can be very emotionally challenging. We hope that we as healthcare professionals can make patients feel comfortable and facilitate this communication to break down the barriers that restrict patients from expressing their worries.”

Professor Axel Merseburger, Onco-Urologist, Germany.

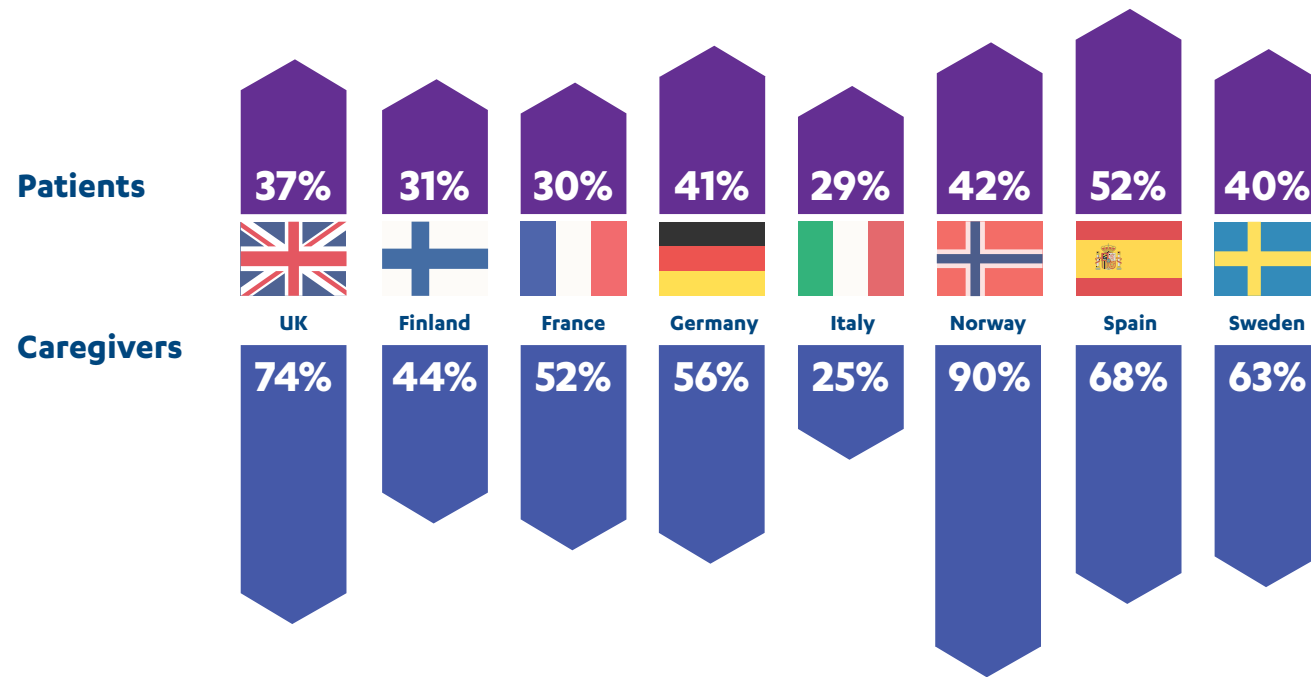
“Being diagnosed with prostate cancer modifies and shapes relationships between patients and their partners. It is true that patients are reluctant to talk about their intimacy problems with their partners. In my opinion, this is because speaking about it clearly is, in some way, admitting to this change in their physical and psychological relationship.”

Christian Arnold, Prostate Cancer Survivor and Vice-President of ANAMACAP, France.



Christian Arnold, Prostate Cancer Survivor and Vice-President of ANAMACAP, France

Figure 2.2
Percentage of those **willing to talk about intimacy** problems associated with prostate cancer with their partner:



Overall, **male healthcare professionals (44%)** are **more likely** to proactively **discuss intimacy** problems with the patient than **female healthcare professionals (33%)**.

Downplaying the physical and emotional problems of prostate cancer

Patients on medication (54%) and those in the metastatic phase of their disease (54%) are more likely to downplay the physical and emotional problems associated with their disease than other patients.

In general, the findings show that **caregivers overestimate how much the patient downplays the quality of life impact** of prostate cancer. 56% of caregivers report that they feel the patient ‘downplays’ his problems. Whereas, **only 41% of patients report that they actually ‘downplay’ the physical and emotional impact** of their disease.





03. Role of Family Members in Supporting Patients with Prostate Cancer

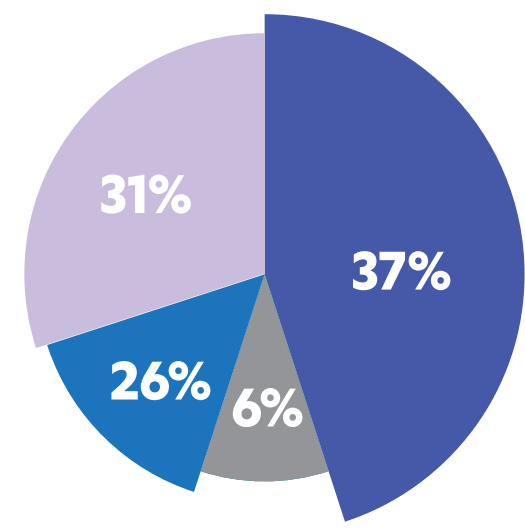
Role of the family

96% of healthcare professionals believe that family support for the patient is important. Additionally, 94% of healthcare professionals involve a patient's close relatives when discussing the patient's condition and 76% (nurses and onco-urologists particularly) report that they provide advice directly to the patient's family or partner.

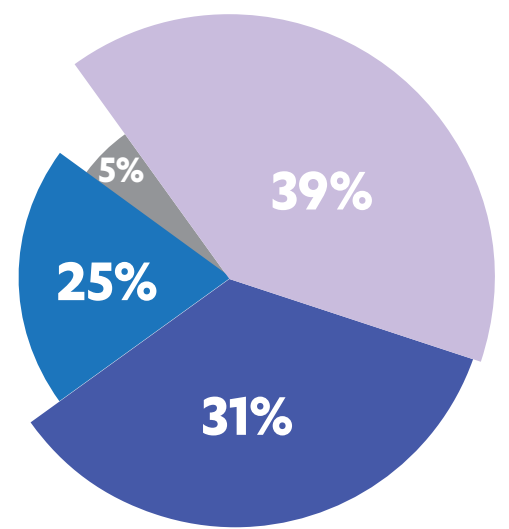
Across Europe, family members who play a big role in sourcing information for the prostate cancer patient also seem to play a significant role in influencing their choice of treatment. Metastatic patients (46%) and those on medication (44%) are more likely to report that their family play a significant role in helping them source information about their disease than other patients.

Figure 3.1
Role of family in sourcing information and influencing choice of treatment:

Role in **sourcing information**:

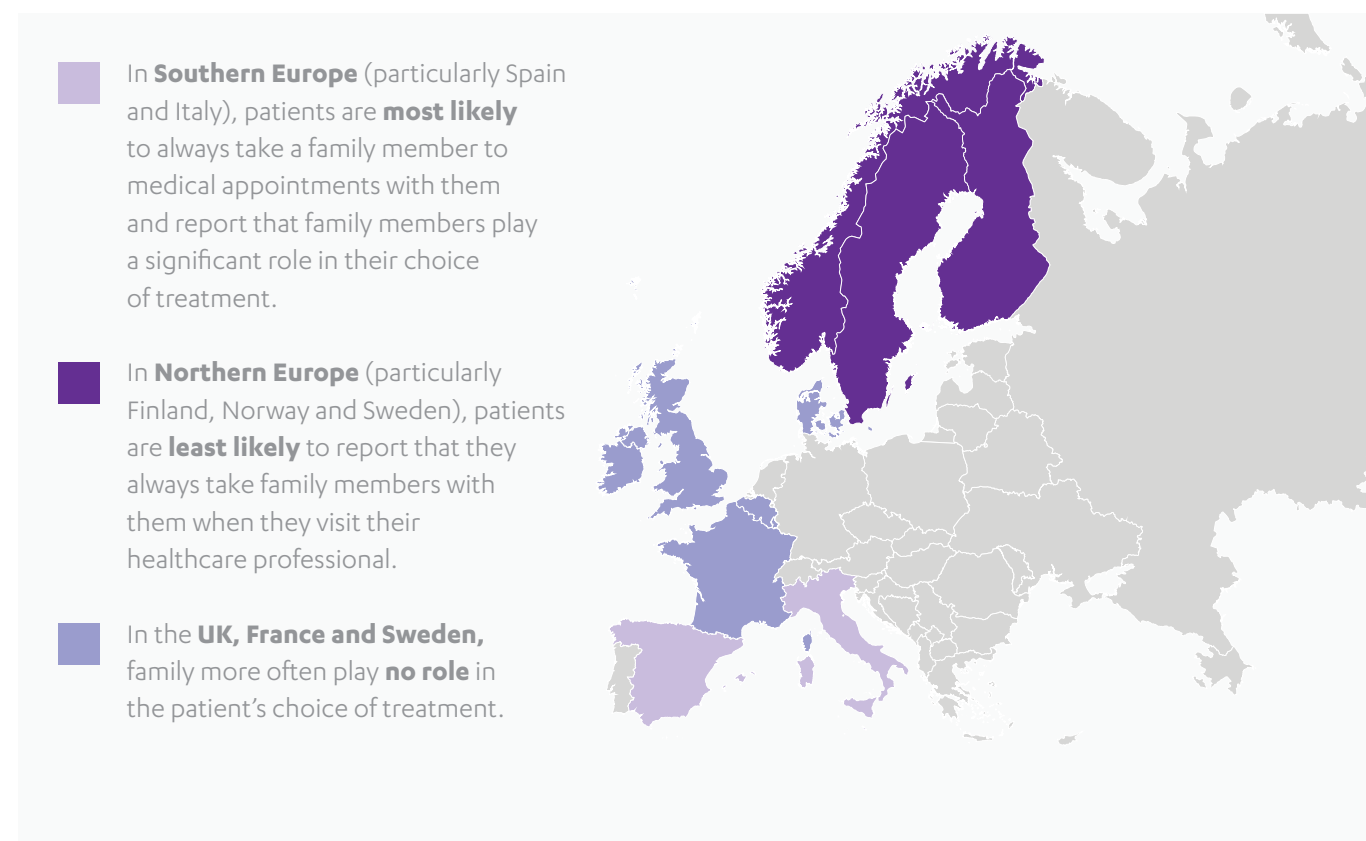


Role in **influencing choice of treatment**:



- Significant role
- No role
- Small role
- Not applicable

Figure 3.2
Role of family in the management of prostate cancer:



“Patients can find it just as hard to involve their family members in both visiting their doctor and managing their disease. This may be because they do not want to burden their family or they feel that, as a man, they are expected to stay strong and deal with their problems themselves. However, family can offer valuable support to patients - that’s why in Sweden, our national guidelines recommend that doctors encourage patients to invite family members to accompany them to their medical appointments. This is so important for the well-being of prostate cancer patients.”

Calle Waller, Vice Chairman, Prostatacancerförbundet, Sweden.

The survey reveals that **family support** is vital in **helping men with prostate cancer to deal with the negative physical and emotional impact of their disease.**

Role of the partner

The patient’s partner is the person in the family most involved in the management process of the patient’s disease. **39% of patients** report that their **partner is the person** in the family **most negatively impacted by their disease**, over their friends (9%) and their children (7%).

“I never see any patient without his partner. Women are much better at asking questions, in understanding, in being assertive when it comes to defending the health of their husband, much better than the patient. You should always see the patient and the partner together. This is the basic rule for getting the best results.”

Professor Louis Denis, Onco-Urologist and Strategic Consultant, Europa Uomo.



Professor Louis Denis, Onco-Urologist and Strategic Consultant, Europa Uomo



04. Support for Patients and Caregivers on Addressing the Quality of Life Impact of Prostate Cancer

Support for patients

Patients feel that **quality of life** is an area that needs to be **more adequately addressed by healthcare professionals.**

87% of patients report that they **prefer to receive advice on ways to improve their quality of life** via **face-to-face discussions** with a healthcare professional.

Patients are most likely to report that they find **emotional and psychological advice (27%) most useful**, over advice provided to their partner/family (20%), physical advice (17%) or nutritional advice (16%).

Figure 4.1

Disconnect between **advice** healthcare professionals report to provide to patients and the advice that patients report to receive:

Only **14%** of patients report that their doctor advises them on ways to **improve their physical and emotional well-being** without using medication.



In contrast, **almost all healthcare professionals (92%)** surveyed report that they **proactively provide advice** to patients on ways to improve their physical and emotional wellbeing.

60% of patients are **not aware of facilities** available at their local hospitals which offer quality of life advice to them and their partners.



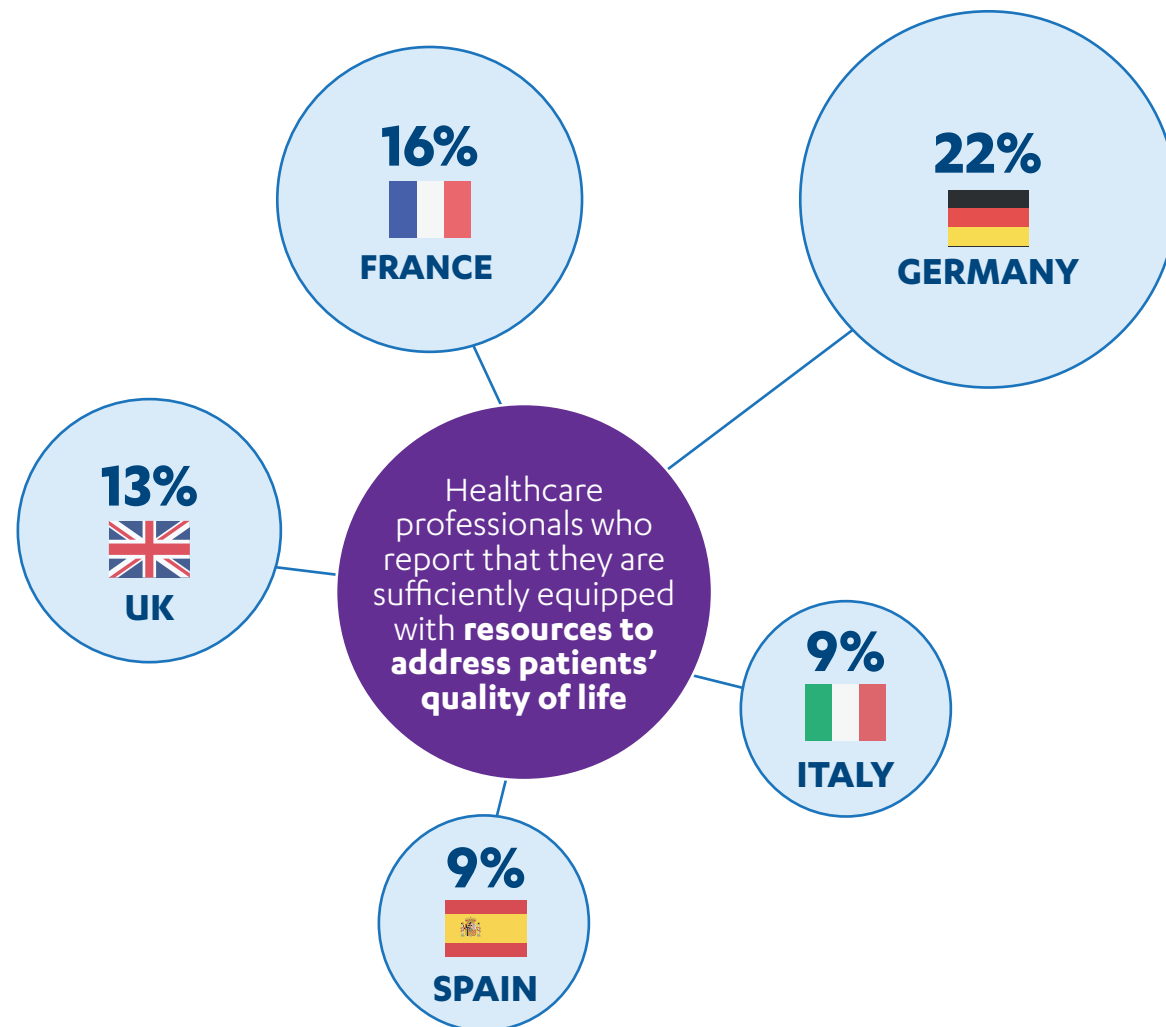
In contrast, **85% of healthcare professionals** report that they **refer patients** to facilities within their local hospitals that can help them to address their physical and emotional problems.

“Managing quality of life is extremely important in the overall process of caring for a patient with prostate cancer. However, there are many complex methods of measuring quality of life, and healthcare professionals may not always be trained in using these methods to identify the needs of patients. It is also often challenging to decide what the best advice is to give to individual patients. I believe more needs to be done to educate healthcare professionals and provide us with the correct resources to give patients the holistic care they need.”

Dr. Maria De Santis, Onco-Urologist, UK.



Figure 4.2 Healthcare professionals who report that they are sufficiently equipped with resources to address patients' quality of life:



Christian Arnold
Prostate Cancer Survivor and
Vice President of ANAMACAP, France

Conclusion

Prostate cancer is a disease that not only affects the physical functioning of a man, but also has a huge impact on his emotions and the lives of those who care for him. As a survivor of this disease, I have experienced how prostate cancer can negatively affect a man's quality of life, and I recognise the true importance of managing these physical and emotional impacts.

The findings highlighted in this report reveal that we must do more to help patients talk about their disease and break down the communication barriers that exist between themselves, their partners, caregivers and healthcare professionals. There is still much work to be done to ensure patients receive the best possible all-round care during this very difficult time in their lives.

I believe there are some immediate actions that can be taken to help achieve a better management of the quality of life of prostate cancer patients. These are:

1. Further educating healthcare professionals and patients

In order to recognise the quality of life needs of prostate cancer patients, we need:

- A single, simple, internationally-recognised quality of life measure to ascertain the impact of prostate cancer and ensure healthcare professionals and patients have a consistent way to identify each patients' quality of life needs
- To communicate to patients and their families the range of support services that exist to help them manage the different aspects of prostate cancer in their lives and be proactive in asking for this help when they need it most
- To provide support to healthcare professionals to equip them with the communication tools they need to help patients from an emotional and physical perspective

2. Facilitating greater patient advocacy group support

In my experience working for ANAMCP and European Uomo, we are seeing an increasing amount of patients looking to patient advocacy groups for support and advice on ways to manage their disease. Patient groups therefore have an obligation to:

- Offer reliable and accurate information about the quality of life impact of the disease and direct patients to where they can get the best help locally
- Provide an opportunity for men with prostate cancer to exchange information with each other about managing the quality of life impact of the disease
- Provide support for men during times when they are struggling emotionally

We have come a long way in the treatment of prostate cancer. We hope that this report shines a light on the changes that must to be introduced across Europe to help improve quality of life and cater to the many needs of men suffering with prostate cancer. It is time to look at prostate cancer differently and allow patients and their families to be able to continue to live their lives as normally as possible.

Christian Arnold

About the Prostate Cancer: Living, not Just Surviving Survey

The **Prostate Cancer: Living, not Just Surviving** survey was initiated following meetings with an independent expert European patient advocacy group panel, who identified that there was a need to widen the breadth of awareness, knowledge and support for men with prostate cancer, as well as focus on the longer-term, holistic (quality of life) needs of these men and their caregivers.

A pan-European survey was then carried out amongst 765 patients, 335 caregivers and 400 healthcare professionals into the physical and emotional impact of prostate cancer. The survey was undertaken by the independent research company, InSites Consulting.

Participants were recruited from online research panels and through patient association group partners. Patients and caregivers were sourced from ten countries across Europe, including: the UK, Finland, France, Germany, Italy, Norway, Spain, Sweden, The Netherlands and Belgium. Healthcare professions were surveyed in the UK, France, Germany, Spain and Italy.

The survey was developed and implemented in partnership with the following expert patient advocacy group panel members:

- Professor Louis Denis – Europa Uomo (EU)
- Christian Arnold – Association Nationale des Malades du Cancer de la Prostate (ANAMACAP) (FR)
- David Smith and Hugh Gunn – Prostate Cancer Support Federation (Tackle Prostate Cancer) (UK)
- Calle Waller – Prostatacancerförbundet (SWE)

This report is dedicated to David Smith, who sadly lost his battle with prostate cancer in March 2015. His input into the **Prostate Cancer: Living, not Just Surviving** survey is a testament to his commitment to raising awareness and helping improve the lives of men with prostate cancer.

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