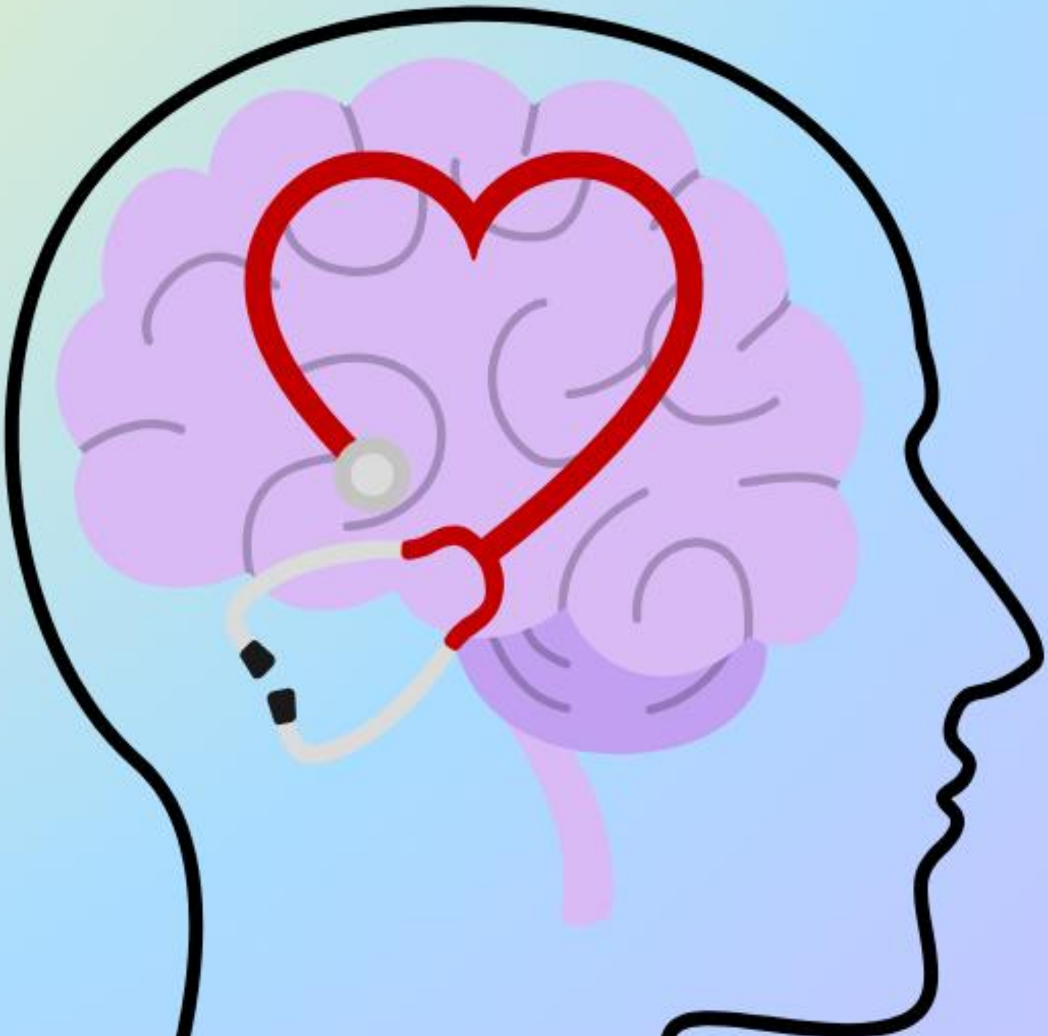
Hearts Left Behind, Minds Left in Battle



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Gaps in emotional and mental health support for adult cancer patients in Switzerland

This system map focuses on the emotional and mental health support for adult cancer patients within Switzerland. The boundary includes all stakeholders and structures directly involved in the system, such as patients, hospitals, NGOs, clinicians, nurses, and insurers. It excludes pediatric cancer care, general mental health issues, and mental health services for cancer patients outside of Switzerland, hereby maintaining a manageable scope for the project. Important environmental influences, such as Swiss cultural attitudes towards mental health, and global health trends are not mapped.

Introduction

In Switzerland, 1 in 5 people are diagnosed with cancer before the age of 70[1]. Between 2017 and 2021, 46,681 new cancer cases were reported, averaging about 9,000 cases per year[2]. These numbers are expected to rise by 2025. Cancer is a physically and **emotionally devastating** disease. Studies show that 35-80% of cancer patients experience significant psychological distress due to the diagnosis, including **adjustment disorder** (8-15,4%), **anxiety** (10-40%), **depression** (5-30%), post-traumatic stress disorder (**PTSD**), psychiatric comorbidity, and diminished quality of life[3–7].

The strong psychological burden is reflected in **elevated suicide** rates[8–10]. In most cases, emotional and mental symptoms are inadequately addressed, diminishing quality of life and increasing healthcare costs[7,11–14]. Severe anxiety and depression in cancer patients are linked to **increased healthcare use** (e.g., emergency department visits, hospitalizations) and rising healthcare costs[15].

Proper cancer care includes managing **physical symptoms, treatment side effects, and addressing psychological needs**. Post-treatment **survivors face fear of recurrence** and **difficulties reintegrating** into society[16–19]. **Social support** may protect against mental illness, while its absence is linked to lower survival rates, though findings are inconsistent[20–24]. However, psychological interventions improve quality of life, an outcome that should never be underestimated[22,25].

Additionally, biological studies have shown that chronic stress suppresses the immune system, increases metastases, and accelerates tumor growth[26,27].

Research results

1. Existing support structures and initiatives

Patient surveys conducted nationwide have shown the lack of psychological and emotional support for patients[28–33]. In Switzerland, several non-governmental organizations (NGOs) and community organizations support cancer patients and their families, such as OSE Therapy[34], and the Swiss Cancer League (SCL)[35]. Most of these focus on holistic approaches[36–39]. Some are cancer-specific (e.g., lung[12], breast[37], or prostate[39]), leaving other types of cancer out. OSE

Therapy is a unique NGO, offering an exclusive model combining creative arts with body-focused therapies, and offering diversity to promote inclusion.

Alongside NGOs, psycho-oncology services emerged in the 1970s, but still face mental health stigma[40]. Oncology teams are not obliged to include psycho-oncologists in their team[41]. The Swiss Society of Psycho-Oncology (SSPO) was founded in 2003, which allowed psycho-oncology treatments and training for the country[42]. Currently, it has 241 members nationwide, mostly in major cities (**Figure 1**)[43]. This number is low relative to patient needs and the projected rise in cancer cases.

1. Barriers and gaps in accessing support

Figure 1. Representation of the map of Switzerland, showing all the cantons colored depending on the number of psycho-oncologists present. Data extracted from the SSPO.

Despite these efforts, barriers persist, especially for foreign, rural, and low-income patients[44]. Cancer patients from rural areas have to be helped remotely or find themselves a psychologist[7]. A quarter of the population are foreigners, therefore they may struggle with language barriers and isolation[45]. Cancer Support Switzerland[46] has adapted to provide support for non-native speakers, it is based in Geneva, limiting access to other regions[47,48].

It has been shown that without screenings for distress, the medical staff fails to identify distress. However, there are no standardized screenings due to several barriers: insufficient training, high workload, lack of resources, language barriers, and patients find screening a waste of time[49].

Despite support structures, access remains limited. Since 2022, psychotherapy is reimbursed but increased demand has led to a shortage of psychotherapists. Is important to note that psychology is still not reimbursed [12,50,51]. Vulnerable groups include elderly, low-income, and rural patients, short-treatment patients, foreigners, young adults, and males [29,33,52–56].

2. Professional training and support for medical staff

Moreover, it has been reported that oncologists and nurses face emotional difficulties as well[57–60]. They manage patient relationships, and institutional regulations, and interact with patients' relatives. Addressing these challenges can strengthen patient-physician relationships and improve patients' emotional health. One key role of psycho-oncologists is to supervise clinicians and nurses, helping them feel more useful and empathic; and less anxious, depressed, and guilty[61].

Since 2005, Swiss oncologists are required to complete 4-6 communication training sessions with a psycho-oncologist or psychiatrist[61–63]. Some universities together with the SCL offer a psycho-oncologist certificate (CAS) involving 8-32 supervised sessions[64–67].

3. Innovation and regional approaches

In parts of the country are trying to implement modern and unique turns to address the issue. Basel University has started a web-based stress management program[12,68]. In Neuchatel, doctors are allowed to prescribe museum visits[69].

4. International models

Different countries have developed tools or strategies to address the mental health needs of cancer patients. The UK uses standardized Reported Experience Measures (PREMs) and incorporates psycho-oncologists in teams with routine distress screening [70–72]. These surveys inform about patients' emotional and psychological support. The UK is working to provide personalized care and support from diagnosis onwards[73]. The US offers survivorship programs (UCSF and Inova) for post-treatment support[74,75]. Germany's Integrated, Cross-Sectoral Psycho-Oncology (isPO) model coordinates care across sectors[76].

5. Root causes and systemic issues

There are various root causes in this system:

- **Stigma and culture**: Stigma around mental health. Emotional distress is perceived as a weakness. Cancer is framed as a battle.
- **Physical health priority**: Stakeholders and funding are focused on physical over emotional care
- **Underfunding and workforce shortage**: Low number of psycho-oncologists. NGOs are underfunded. Support is limited to main cities.
- **Lack of screening and integration**: No routine distress screening. Medical care is fragmented. Limited communication between specialists.
- **Financial barriers**: Limited reimbursement of psychological support by the insurance companies.
- **Unequal access**: Foreign, rural, and minority patients face extra barriers (language, distance, isolation, reduced screening). Survivorship support is limited.

Interview and survey results

Separate surveys with multiple-choice and open-ended questions were conducted for 8 oncologists, 2 nurses, and 14 patients. Additionally, interviews were done with 2 oncologists, 1 psycho-oncologist, 4 patients, and 1 NGO. The study was limited to the canton of Vaud. Quotes appear in brackets and italics.

1. Medical staff

The main results are summaries in **Figure 2**, showing that clinicians observe that patients struggle emotionally and mentally. However, clinicians struggle to find support for their

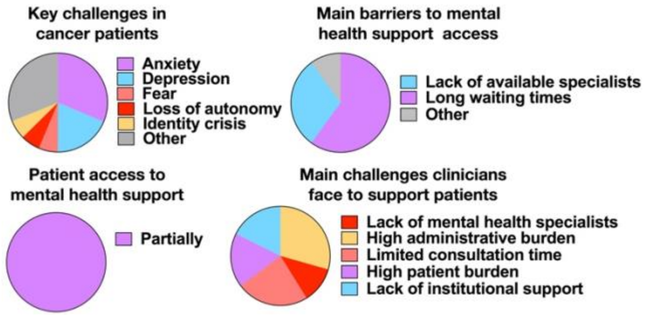


Figure 2. Shows the main results obtained from the surveys and interviews performed with oncologists.

patients, as services are only partially available. Several barriers regarding mental health support were identified by clinicians, “*finding a psychologist/psychiatrist*”, “*lack of prioritization*”, and “*lack of availability of specialists*”. Clinicians have only between 15-30min per patient to asses physical and mental health, which is “*not enough time*”. Only 2 clinicians have received formal psycho-oncology training, and one of them stated that the level of adequacy was medium-to-low, hence the majority would appreciate more “*training/supervision and closer collaboration*” with psycho-oncologists. Additionally, clinicians face several challenges in providing better support for their patients. When asked about discussing mental health issues with their patients most clinicians feel “*afraid to discuss it*” and feel “*not entitled to do so, because*” they “*don’t know about the topic*”, they “*want to protect*” themselves, so they wait for that *“the patient brings it up*”. Finally, one clinician identified that the stigma around mental health is still very present, a “*great barrier among patients to accept this kind of support*”, and “*among oncologists, we don’t talk about it*” for fear of getting into “*an uncomfortable situation*”, and finally she believes that “*judging patients who are depressed still exists*”.

Psycho-oncologists often feel overwhelmed by patient numbers. One described being “*alone*” in her unit, making it “*impossible*” to treat everyone: “*There were patients I wanted to follow more carefully, but couldn’t*”. She left the hospital to work independently, where many patients came to her “*because the support in the hospital was not good*”. However, since her services aren’t covered by insurance, “*it was not an option for many*”. She believes oncologists should be “*obliged to do psychotherapy*”.

2. Patients

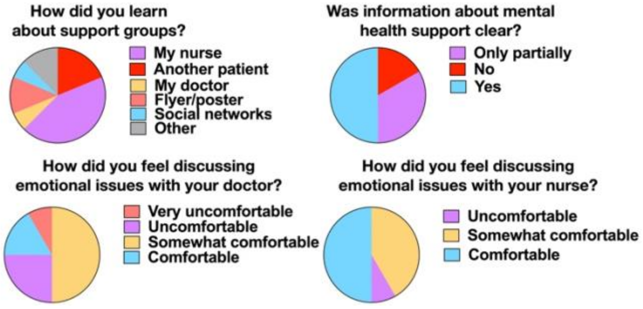


Figure 3. Shows the main results obtained from the surveys and interviews performed with cancer patients.

Upon diagnosis patients describe feeling “*terrorized, devastated*”, and “*devastated. Lost. Punished.*”. Those who attended support groups such as OSE therapy or LVC found it “*enormously helpful*”, often learning about them through their nurse or other patients. What helped most patients was “*listening and sharing”, “physical and recreational activities*”, and “*therapy*”.

While many felt, somewhat comfortable discussing emotional issues with their doctor, they felt comfortable with nurses. Observed barriers with oncologists include: *“lack of time*”, “*better communication*”, “*lack of empathy*”, “*undergoing therapy themselves”,* and “*don't keep* *changing assistant doctors*". One patient observed that doctors seemed "*scared if the patient in front cries*".

Discrimination was also mentioned: "*taking advantage of my vulnerability because I was alone*". Some patients faced logistical barriers: "*difficulties getting to treatment as it's very far", and "difficulties cooking, cleaning*". Financial issues were experienced: patients couldn't "*access proper care and support*", and "*psychologists' support became too expensive*".

Patients in remission "*struggle a lot*" with reintegrating. Others "*expect*" them to be "*happy, normal, able*", while they feel "*exhausted*", their "*body is destroyed*", and they have to "*deal with trauma, depression, and anxiety*", alongside the persistent "*fear of recurrence*".

All patients reported an "*enormous lack of support*". In general NGOs, such as OSE therapy and LVC were praised for providing essential, low/no-cost support throughout their journey.

3. NGOs

OSE therapy was founded in 2019 with the belief that "*patients should not only survive but also feel pleasure, re-connect with their bodies*" and that "*movement is life*,". It emerged in response to patients' "*suffering*" and the lack of support. Since then, it has struggled with "*recognition*," "*funding*," and COVID-19. "*In December 2023, we were normally closed, but patients started fundraising*," which helped OSE survive. Finally, OSE obtained public recognition and formed stronger ties with clinicians.

After two years OSE has identified key issues: patients receive support information too early, when they are in "*shock*" and " *often forget*." In fact, "*a patient had to ask ChatGPT where to get help*." A major challenge that OSE has identified is "*trouble adapting*" to every aspect of life. Remission is especially difficult: "*After diagnosis patients enter a phase I call the 'washing machine'... they just do what they are told. Once in remission, they are left alone, patients feel lost*," while loved ones "*expect them to go back to who they were, but the patients cannot*."

Although OSE supports all genders and cancer types, it's often mistaken as "*only for women with breast cancer*." Greater awareness makes it easier for these women to seek help, while "*women with other cancers feel guilty, not legitimate*." Patients appreciate the efforts made by OSE therapy and other NGOs, saying "*OSE is a sacred place*", and saying NGOs "*are worth gold*".

Casual loop map

Using all the research collected I have generated a casual loop map showcasing 7 main loops (**Figure 4**). Access: https://kumu.io/PGuerr/mental-health-care-in-cancer#casual-loop.

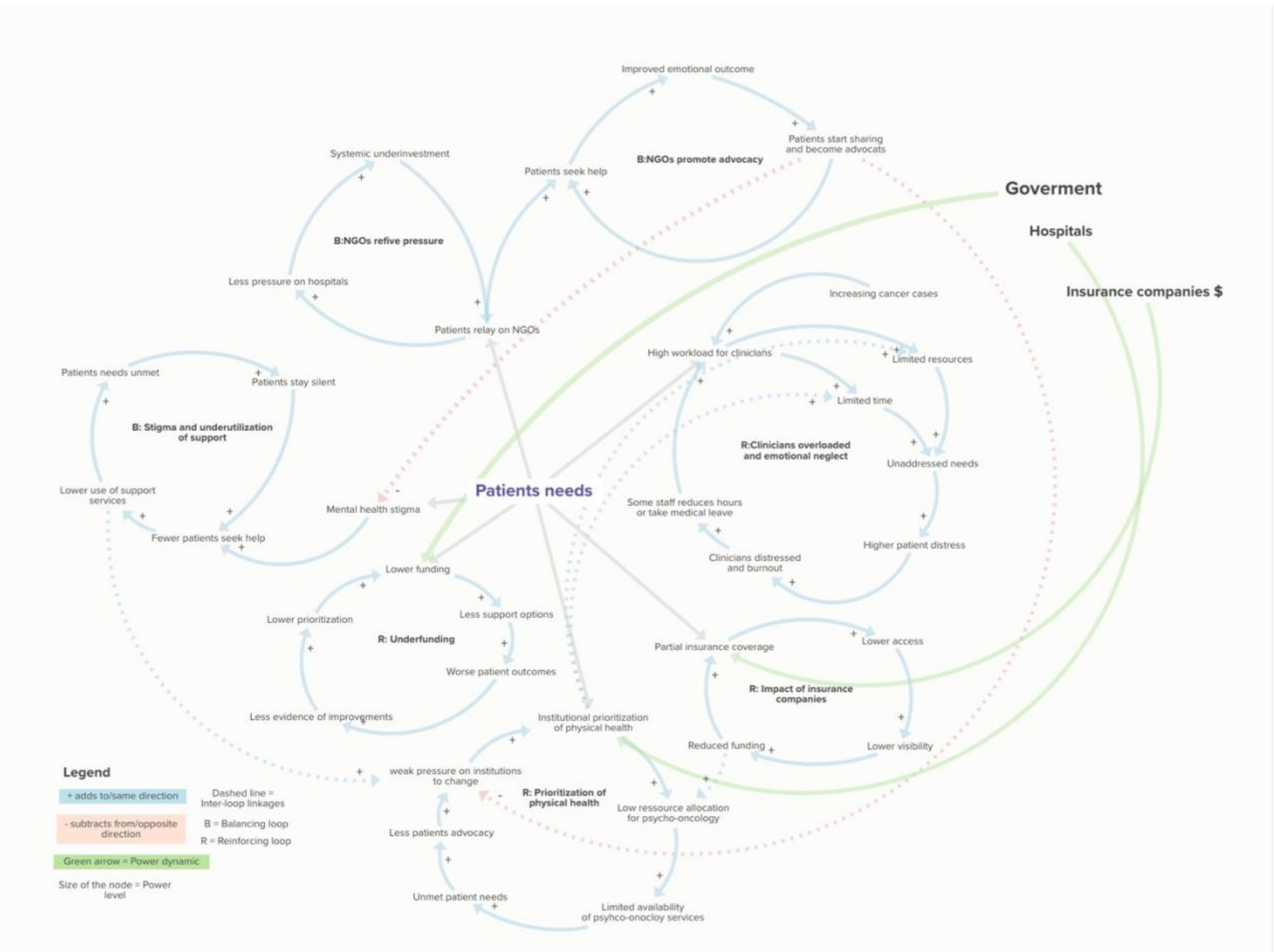
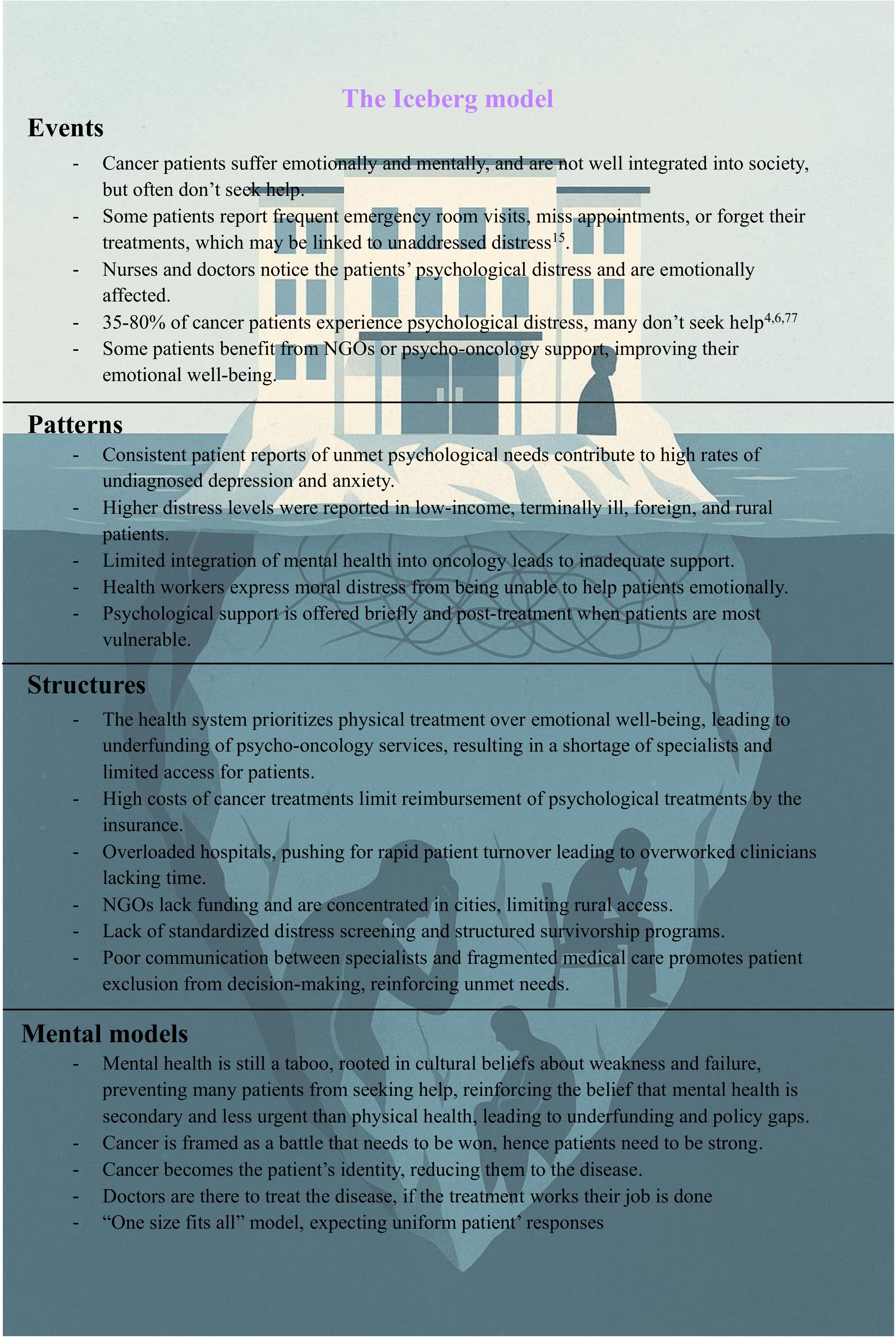


Figure 4. Casual loop map.



The Iceberg model

Events

- Cancer patients suffer emotionally and mentally, and are not well integrated into society, but often don't seek help.
- Some patients report frequent emergency room visits, miss appointments, or forget their treatments, which may be linked to unaddressed distress[15].
- Nurses and doctors notice the patients' psychological distress and are emotionally affected.
- 35-80% of cancer patients experience psychological distress, many don't seek help[4,6,77]
- Some patients benefit from NGOs or psycho-oncology support, improving their emotional well-being.

Patterns

- Consistent patient reports of unmet psychological needs contribute to high rates of undiagnosed depression and anxiety.
- Higher distress levels were reported in low-income, terminally ill, foreign, and rural patients.
- Limited integration of mental health into oncology leads to inadequate support.
- Health workers express moral distress from being unable to help patients emotionally.
- Psychological support is offered briefly and post-treatment when patients are most vulnerable.

Structures

- The health system prioritizes physical treatment over emotional well-being, leading to underfunding of psycho-oncology services, resulting in a shortage of specialists and limited access for patients.
- High costs of cancer treatments limit reimbursement of psychological treatments by the insurance.
- Overloaded hospitals, pushing for rapid patient turnover leading to overworked clinicians lacking time.
- NGOs lack funding and are concentrated in cities, limiting rural access.
- Lack of standardized distress screening and structured survivorship programs.
- Poor communication between specialists and fragmented medical care promotes patient exclusion from decision-making, reinforcing unmet needs.

Mental models

- Mental health is still a taboo, rooted in cultural beliefs about weakness and failure, preventing many patients from seeking help, reinforcing the belief that mental health is secondary and less urgent than physical health, leading to underfunding and policy gaps.
- Cancer is framed as a battle that needs to be won, hence patients need to be strong.
- Cancer becomes the patient's identity, reducing them to the disease.
- Doctors are there to treat the disease, if the treatment works their job is done
- "One size fits all" model, expecting uniform patient' responses

Levers of change

Lever	**Stakeholders involved**	**Challenges**	**Solutions**	**Positive outcome**	**Negative outcome**
Include standardized and national routine distress screening.	Hospitals, government, insurers	Time, resources, training	Perform screening electronically, hospitals should receive funding, and provide proper training.	Early intervention and patient referral, patient needs are met, improved quality of life.	Reduced invisibility leads to an increased number of patient referrals and overwhelms the system.
Create structured national survivorship programs.	Government, insurers, NGOs, survivors	Funding, specialists, training, patient engagement, coordination	Make a pilot program where hospitals, patients, and NGOs collaborate to improve the program, learn and re-adapt the program, and allocate resources appropriately.	Survivors' needs are met, they can better re-integrate into society, improve mental health, and reduce isolation.	Unequal access for all patients (eg language, economic, rural barriers). Underutilization if not well-implemented. Funding issues.
Integrate psycho-oncology nationwide.	Hospitals, clinicians, psycho-oncologists, government, insurers	Resources, workforce, culture, stigma	Mandatory training for all medical staff, embedded psycho-oncology into routine cancer care.	Improved communication and awareness. Releases pressure on oncologists and nurses. Patients' mental health improves.	Clinicians may resist and feel less useful or attacked. Funding instability.

Improve awareness around mental health.	Government, universities, schools, specialists, patients, NGOs	Funding, resources, culture	Promote early education of mental health and public campaigns, as well as patient advocacy.	Reduced stigma around mental health, the problem becomes visible. More patients seek help.	Increased discrimination, this change takes a lot of time and effort.

From the proposed levers of change:

- The inclusion of distress screening may be the easiest and fastest to apply. Already a few questions can help identify patients in need. This change will help make the problem visible and push institutional change if done correctly[72].

Key insights and lessons learned

This experience has been deeply enriching, as I was unfamiliar with system thinking. I expected a simpler system and few support centers for patients, but found a complex network of NGOs and psycho-oncologists. However, I found that these supports don't fully address the system's challenges, which are shaped by the persistent mental health stigma and the cancer as a "battle" mindset. I also learned how vulnerable medical staff are, and realized that supporting their well-being and promoting training is just as crucial as focusing on patients, as both are essential both patient-clinician relationships.

Before this research, I didn't expect cancer survivors to need ongoing support. I now see, that there is a big gap, many survivors struggle with severe exhaustion, returning to work, pressure to appear happy, trauma, anxiety, persistent fear of recurrence, and loneliness. I recommend increased promotion and funding of survivorship programs.

Mental health is present in many systems, such as other diseases (e.g. autoimmunity, dyslexia), education, social services, and homelessness. Therefore by addressing the stigma around mental health other systems can also benefit.

A key limitation of the study is that only stakeholders from Vaud could be interviewed due to lack of time, this reduces the inclusivity of the study.

I thank the medical staff, patients, and NGOs who participated in the surveys and interviews. I hope this helps them better understand their system.

Patients have real power in their voices, can pressure institutions, reduce mental health stigma, and promote patient-centered care. I want to entice medical professionals and hospitals to advocate for proper training and routine distress screenings. Open conversations among clinicians, patients, and NGOs will help reduce stigma and make it easier for everyone to discuss these issues.

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