

Cancer Path in Switzerland: Making the Patient an Ally to Increase Health Outcomes and Quality of Life

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Abstract

Background

Prevalence, complexity and costs of cancer care are increasing in Switzerland. Losses in efficiency, resources and inadequate attribution hamper health outcomes. This study investigated possibilities for improvement across the whole cancer path, with a special focus on patients-care provider communication and effective approaches to strengthening interprofessional collaboration.

Methods

Key stakeholders were selected based on their expertise in different areas of the cancer path and were invited to take part in interviews. Subsequently, a DELPHI-like method was applied, followed by two focus groups.

Results

There is a prominent need for collaboration and trans-sectoral action in cancer care, encompassing clinical disciplines, communication strategies and professional attitudes. The necessity and demand for collaboration meets a highly fragmented landscape of cancer in Switzerland with a hierarchical organization of medical care entities and competition.

Conclusions

Pressing developments are happening in the healthcare system given the rising prevalence of some cancers, the demographics of the Swiss population and the growing number of cancer survivors. More fundamental solutions should be developed and implemented to meet patients' needs and improve health outcomes: Are care providers and patients assuming their responsibilities for change? Will economic interests and power games boycott this change? The article tries to respond.

Background

Cancer is, and remains, one of the most critical challenges for the Swiss health care system. According to epidemiological estimates, around 40,000 people in Switzerland are diagnosed with cancer every year, one in three people are diagnosed with cancer in their lifetime and one in four deaths are due to cancer [1]. The overall cancer prevalence is similar amongst the French, Italian and German language regions. There are, however, conspicuous differences in prevalence for a few specific cancer types and patient groups, e.g. for hepatic, cervical, testicular and thyroid cancer [2]. The Swiss reference for cancer management is the National Cancer Strategy (SNC, 2014–2020) [1].

Patients, their families, and their health care team face many issues when cancer is diagnosed. Good communication can help patients, families, and doctors make these decisions together and improve the patient's well-being and quality of life [3]. Patients' beliefs, values, the meaning of the illness, preferences,

and needs are fundamental elements in constructing a trusting relationship, finding common ground, being open to discussing and providing information tailored to suit the patient's level of understanding [4]. The emergence of emotions like anxiety, irritation, and sadness can inhibit caregivers from offering adequate support in moments of distress [5]. In Switzerland, there is a strong movement at a national policy level towards strengthening patients' rights and involvement in health care decisions. Yet, there is no national program promoting shared decision making. Although Swiss doctors acknowledge that shared decision-making is important, hierarchical structures and asymmetric physician-patient relationships are still prevailing [6].

The cancer path is long and complex and given the range and number of health-care professionals involved, there is potential for poor management and high competition. An interprofessional approach, with effective collaboration, coordination and shared decision making process between care providers and the patient are key steps to reduce patient stress, work overload on both patients and professionals' sides, and to build trust across the care continuum [7, 8]. Oncology nurses can play a pivotal role in facilitating interprofessional collaboration, optimizing the care of patients and provide long term follow up [9].

This multifaceted scenario applies not only to cancer patients but also to survivors; in Switzerland, although 10-year post-diagnosis cancer survivors make up only 2.4% of the general population, the proportion among those aged 70 or older is a staggering 23–25%, depending on the language region. Currently, about 320,000 people with a previous cancer diagnosis are living in Switzerland, among them are many "long-term survivors". Thus, it is becoming increasingly relevant to account for the specific health care needs of vulnerable groups to ensure that all long-term and wellness needs are met [10–12]. These needs include monitoring and managing persistent and late physical and psychological effects, prevention of poor health, and promotion of good health, in addition to surveillance targeting of co-morbidity illnesses, health care coordination and social inclusion [2, 11].

This study aims to assess the needs of cancer path in Switzerland, covering the three main linguistic areas of the country, with a special focus on the patient – care provider relationship to facilitate effective approaches and investments in the cancer pathway.

Methods

Previously conducted surveys evaluating the cancer path with a special focus on patient perspectives and needs, and on their relation with care providers, were investigated. Insights gathered from the surveys were combined with assessment expectations, to develop a quali-quantitative survey. A literature review was also performed to define the state of art in cancer care in Switzerland (results not published in this article). After the initial phase of contextualization, a questionnaire was developed to investigate the perspectives of patients, support groups, as well as professionals working in cancer care or prevention, by using tailored questions (Annex 1). The survey was pre-tested by selected experts and subsequently

translated into German, French and Italian. The local ethics committee « Commission cantonale d'éthique de la recherche CCER – HUG » ruled that no formal ethics approval was required in this particular case.

30 experts from different fields were invited to contribute to the study and 27 agreed to participate, with a significantly high response rate of 90%. Experts were selected based on their expertise in different areas of the broad cancer path, both at federal and cantonal levels. 59.3% were from the German speaking area, 29.6% from the French area and 11.1% from the Italian area (working area of the experts). The highest participation from the German cantons relates to the location of the cancer organization headquarters in Bern or Basel. 11.1% of the respondents to the questionnaire were cancer patients and some interviewees had personal experience of close relatives with cancer. There was a good gender split across respondents with 55.6% of questionnaires completed by females and 44.4% by males. Experts covered a considerably broad range of professions and roles such as academic/researcher, doctor, economist, epidemiologist, journalist, lawyer, nurse, patient, patients' rights activist/supporter, pharmacist, politician, social worker, etc. Several wore multiple hats; for example, doctor, lawyer and patient or doctor and researcher or pharmacist and epidemiologist. The experts represented professions from most of the key areas of the cancer path including cancer support community, cancer registry, cancer screening program, cancer support association, canton health services, and hospital/cancer center, journal, law association, federal and national offices, pharmaceutical company, social services, university, etc.

Respondents were invited to elaborate on their perspectives via in-person interviews or, if not possible, telephone interviews. Data collected were analyzed. A DELPHI-like method was applied, and two focus groups of experts met via teleconference and discussed the outcomes, potential recommendations, and divergences.

The present study uses mainly qualitative methods that aim to gather the perceptions of participants and gain a deeper understanding of the way health professionals and patients view the cancer care system. Selected citations are reported in the results.

Results

Numerous key needs and areas of improvement were defined by the respondents. Several cross-cutting issues arose as a result of our analysis. In this article we focus on the patient - care provider relationship and on ways to improve health outcomes and quality of life through effective collaboration and communication.

Moving out of silos

“Many doctors don’t think they need to discuss nor collaborate with other doctors or health professionals and focus on their specific part before sending the patient to the next specialist that will do his/her part”

“We observe more competition than collaboration among care providers...bias to collaboration are built in the system”

“Interdisciplinarity means that every professional gives his/her competencies at every stage of the path”

“All professionals and patients should have the same objective of care and use the same vocabulary to understand each other and communicate efficiently”

“Now often patients migrate among different specialists, get confusing information and search on the internet, thus creating even more confusion and lack of confidence in the health system”

“An effective multidisciplinary team will be able to reduce the bureaucratic workload and provide additional key services such as a hotline 24h/24 lead by the multidisciplinary team, aware of the patient condition and path, to answer to questions and provide support during and post treatment”

It was frequently reported that the integration of different disciplines and the implementation of a multiprofessional approach remains weak. As such, it was emphasized that a more cooperative form of care, including a platform which involves all professionals and the patients, should be developed. A key requirement is the set-up of a multidisciplinary team based on mutual respect of all professionals, addressing the need of providing both a broad overview and personalized information to patients. Competition among care providers was highlighted as a key barrier to effective collaboration.

Several initiatives were suggested by the interviewees: both top down (legal framework) as well as bottom-up approaches were proposed to develop concrete projects and incentivize local initiatives, as well as to put politicians under pressure. Additionally, to facilitate this revolution and break the silos, a change in education through compulsory intersectoral education should be provided at university, followed by periodical training of health professionals on communication. The training should not only focus on interprofessional collaboration but also on increasing professionals’ sensitivity when talking with patients. Common training of doctors and nurses at university and in the workplace was strongly encouraged to facilitate the development of respect, trust and to reduce stress in the workplace. However, this kind of approach remains rare with only a few exceptions. More effective work sharing among doctors and nurses may lead to the most effective treatment and follow up as well as to a reduction of the bureaucracy load for doctors.

Interviewees highlighted that intersectoral education should be reflected in the set-up of cancer centers hosting all cancer specialists under the same roof, with nurses coordinating the different specialists and acting as the link between the healthcare professionals and patients. The team should be able to rely on different professionals with an understanding on personalized and genetic medicine and a public health perspective. The multidisciplinary center for breast cancer in Lugano and the Tumor Board at CHUV in Lausanne, along with other multidisciplinary tumor boards in the country, offer interesting examples of

applied multidisciplinary. Similar approaches should be available for all cancers in each canton. Harmonization of the tumor board will also be in the focus of the next federal cancer strategy.

Interviewees agreed that effective multiprofessionalism with tasks and responsibility shared between professions would not only improve the services received by patients and improve health outcomes, but would also increase patient understanding and confidence, as well as reduce costs and the paperwork overload for doctors and patients. Indeed, with the current system, patients must explain and set up a medical dossier with each cancer professional, resulting in a considerable loss of time and energy for all people involved. A possible solution relies on a multidisciplinary team and the creation of an e-dossier shared between all professionals. This would require all professionals to read the report developed by other specialists (i.e. doctors and nurses). The adoption of a common language would assist this task, as different terminology is used among diverse kinds of health professionals. This approach should also embed general practitioners that are often the first contact for the cancer patient.

Communication: is it focused or fragmented?

“In Switzerland communication is fragmented, not always addressed to the target population, with patients confronted to conflicts of information and fake news”

“Fake news based on personal opinions on screening are easily transmitted through social media questioning evidence-based studies”

“Patients should get tailored information and material to guide them through the path including how exams work, how the treatment will work for the patient, information dealing with organizations and support groups in the region”

“We need a centralized national program with communication to raise awareness and push national agenda”

It was frequently reported that having the right information at the right time is key for both patients and decision-makers. Interviewees underlined that while important communication strategies are performed regarding screening by certain cantons, communication on cancer prevention remains weak. Talking about cancer can be hard, cancer is often stigmatized, and additional awareness within the community is needed. Development of interactive websites and apps, as well as appropriate use of social media, have the potential to profoundly increase community and patient understanding, create more data and sustain advocacy. This has been done in Germany where an effective approach to the communication for breast cancer screening has been developed at the national level. Interviewees also underlined that effective use of media and social media will be essential to evaluate and monitor patient needs in cancer centers, as is currently done in the UK, Canada and US.

(Inefficient) Patient-doctor relationships

"In Switzerland there is a paternalistic attitude of doctors, and patients generally obey...there are too many doctors with a deep interest on economic return rather than on the services for the populations or tools to reduce cancer incidence"

"This money-driven approach is also an outcome of the current health insurance system that privilege certain kind of professionals and treatments"

"A possible even if extremely complex idea to increase doctors' quality of work and potentially reduce health system expenses is to change [the current] doctor payment system. Nowadays doctors are paid for what they do which, in many cases, leads to the prescription of too many analyses, often not needed, thus increasing a lot the healthcare costs and insurance costs for the public. If doctors are paid with monthly salary, over-treatment and analyses may be reduced, with the potential to reduce costs [while] maintaining the same outcomes. However, the risk to pay also "lazy" doctors remains"

For the patient-doctor relationship, several problems were outlined. Many lay people simply trust their doctor without having any guarantee on the quality of the service they receive, with doctors often putting pressure on patients to intervene to avoid losing patients and income. Moreover, many doctors are worried about making mistakes and therefore are skeptical about trying novel approaches outside of standard protocols, with the risks of blocking valuable innovation and knowledge due to concern over legal consequences. For the majority of doctors, the economic model and its consequences on treatment and prescriptions are not obvious.

Is the patient an ally?

"Care providers should stay patient- and family - centered for every single step of the path"

"While treatments [themselves] are high quality, we need a change in the system to embed and respect patients' choice in the decision-making process"

"[The] patient is an ally and not a passive listener, [and] should be [a] member of the treatment team to jointly decide the best approach for him/her"

"Engaging with patients and their family is not easy and medical language is a slang not understood by most patients"

It was often reported that cancer services in Switzerland meet patient needs on several aspects such as diagnostics, the number of doctors, centers, structures and treatment. However, it was indicated that gaps exist in specific highly vulnerable subgroups such as the elderly and illegal residents "sans papier". Moreover, much more should be done on psycho-social support, stigmatization, communication, prevention, palliative care, life after cancer and on end of life support. According to interviewees, creating and nurturing a base of trust with patients and their family, getting accurate information and understanding their cancer path, play a key role. Additionally, patient empowerment has been scientifically demonstrated to help improve outcomes.

“More discussion with patients and family will reduce over-treatment and increase patients expected outcomes, especially at end of life”

“The role of family and the amount of support provided to the patients vary a lot according to the cultural background of the patients...in Ticino, family is really present and takes active part in the discussion”

“In most cases, empowerment is usually reached at the end of the path while patients would need a clear discussion with [the] doctor at the beginning to be part of the decision-making process”

“Language is one of the main barriers for [the] patient...this is true for the exchange patients - care providers as well for making advocacy at federal level”

“Patients often don’t read English and have so limited access to scientific studies”

Several interviewees have underlined that increasing patient literacy on cancer, starting from prevention to better communication of objective data, higher presence in the media, at public meetings, with patients’ group and in the community is key. Patients should be empowered to understand each step of the path and not merely passively follow doctor advice. However, even if advanced centers start integrating patients in the discussion, including in the clinical trial commission, most patients are not informed nor trained and thus cannot perform effective advocacy.

Some interviewees have emphasized that patients should be treated in a language they know well to be able to understand the treatment, make a choice and comply with it. It could happen for example that an Italian speaking patient lives in a German-speaking canton but, even if speaking German reasonably well, this level is not enough to completely understand the cancer path and fully express his/her needs and intimate concerns in that language.

Scientific studies and trials are often in English. This is the same for the language spoken within teams and committees, thus limiting real patient participation from local to federal levels. Cultural interpreters have been proposed to facilitate the communication and participation of patients in the debate at all levels as well as to help translation of their message to politicians.

Increasing efficiency & adherence: nurturing confidence and reducing stress

“Considering that the roles of doctors and nurses in the cancer path are different, complementary and equally needed, there is still too limited investment in nurses and especially cancer nurses, as well as lack of recognition”

“Advanced education such as Advanced Practice Nurse (APN) post-graduate education should be appropriately recognized with clear roles and responsibility and an appropriate salary”

“Nurses are covering on long term an important part of the cancer path...their role, for instance subordinated to doctor decisions, responsibility and recognition need better definition”

“Nurses can play a pivotal role as navigators, since they know patients as persons and not as a disease like doctors.... Patients and families are insecure and need a nurse navigator to coordinate the journey and follow up of survivors or in case of relapse”

“When medical treatments are less aggressive, psychological support is more in the focus of patients... while psychological support during treatment is more easily provided by the hospital, it is more difficult to receive it afterwards”

“Psychologists are a cost for hospitals since their work is only partially covered by the services provided reimbursed by the health insurance; not reimbursed services include also talking with patients that, as consequences, is not generally part on the care providers’ approach”

Some interviewees have recommended that the first person a cancer patient should meet in hospital is the head nurse, and that this nurse then remains their reference along the cancer path. This could lead to reduced stress, an increased sense of trust and the feeling of being listened to, heard and cared for. This approach should not be limited merely to information and emotional support but also applied more broadly to concrete help to ensure that real needs are met quickly. Some interviewees highlighted that in large hospitals there is a certification process that includes a screening for psychosocial distress to recognize this suffering and provide needed support. This was considered an effective measure with high impact in the long term. In addition to this screening, it was suggested that psychologists and health professionals have time to talk with patients and family, especially about their needs on a deeper level in the discussion. Of note, even when psychological support is proposed by oncologists, which unfortunately is not common, it is not always welcomed by patients and their family and new schemes to increase acceptability to change this behavior need to be developed, interviewees said. To implement psychological support, a multi-step approach was proposed with oncologists understanding and proposing this support, hospitals investing more in hiring onco-psychologists and the need to adapt the reimbursement system accordingly. An interviewee has proposed to introduce the “Buddy support team” in Switzerland, an approach that has been used for many years in Australia. In this system, patients in hospitals are asked if they want to be contacted by a survivor that matches for age, cancer type, etc. The survivor has experienced the whole path, is healthy and has received some training. In Switzerland, this approach is not available due to complex bureaucracy and opposition by psychologists.

Life beyond treatment: palliative care & survivorship

“Palliative care it’s inappropriately considered just for the end of life... earlier screening for palliative care needs and subsequent introduction will increase patients’ quality of life also during the treatment”

“Palliative care at the end of life is getting more and more complex due to all new therapies that potentially patients try up to the end, which make the boundary of palliative care much less defined”

“Patients often prefer to stay at home as long as possible with appropriate support up to the end; however, it’s not possible in most of case because of the very few hours of services per day reimbursed”

“Cancer survivorship is increasing but patients don’t see a path after treatment and feel left alone”

“We should focus on onco-rehabilitation, digital health support managed by patients and psychological complementary therapy in the survival part including self-confidence

It was frequently reported that effective palliative care is an unmet patient need, with important differences among cantons. For example, palliative care and psychological support are extensively developed in Vaud, but remain a real concern in other areas. Interviewees highlighted the need to increase efficiency through better and earlier collaboration among oncologists and palliative care providers by training all health professionals dealing with cancer in palliative care, as well as by introducing a palliative care peer group in every unit. Training of health professionals would be key since they often do not feel comfortable speaking about palliative care, thus creating a taboo around the topic among patients. Patients need better links and coordination among hospitals, general practitioners and home care since patients do not spend much time in hospital and most treatments are ambulatory.

Another unmet patient need frequently reported by interviewees is life after cancer. There is a lack of understanding of survivorship and of survivors’ problems and needs (medical, at the workplace, social, cosmetic, etc.). The survivorship programs should have an integrated oncology and mind-body approach. Not only should the health sector be part of this long-term re-integration, but society at whole. For example, employers can support cancer employees through allowing them to participate in social activities at the firm thus giving survivors a better sense of belonging and feeling of a normal life.

Discussion

The study was well received and matched interviewees’ need to talk about the cancer path in Switzerland and the ways to implement it. All stakeholders were eager to participate and to add their views. This can be perceived as a sign of the timeliness of the study. The high participation rate is also a testimony of the commitment of the interviewed professionals to the Swiss health care system. Professionals and users show a strong connection with “their” system.

As an overall ascertainment from all participants, there are numerous reasons to change the cancer pathway in Switzerland. The recognition of the positive aspects of the Swiss health care system are underpinned by almost all, but at the same time, there is an urgent need for improvement in parts of the system, as outlined.

There is a prominent need for collaboration and trans sectoral action in cancer, maybe even more than in other health domains. This particular point was emphasised by interviewees. Collaboration should encompass clinical disciplines, communication strategies, bureaucratic continuity, professional attitudes, and many other areas. In almost all interviews, a lack of collaboration and / or a hindrance to optimal collaboration at different levels was mentioned.

The necessity for collaboration meets a highly fragmented landscape of cancer care in Switzerland. On the medical side, collaboration is not in the DNA of all health professionals. There are longstanding traditions that have perpetuated the hierarchical organization of medical care entities. The well-documented benefits of a team-approach in cancer care can take time to be implemented. The difficulty for change is well-grounded in a payment system that does not favor collaboration but instead fosters individual activities. In such a system communication is also fragmented. There are losses of both efficiency and humanity as patients, the weakest in the health care system, will have to struggle the most to get their needs fulfilled.

Collaboration is also hampered by the prevailing in-built competition of the current system. The role of competition in healthcare is much debated. Despite a wealth of international experience in relation to competition, the evidence is mixed and contested and the debate about the potential role for competition is often polarized [13]. Health as a common good is limited by the prevailing market economy and softened by the mandatory health insurance system. Cancer and its consequences often exceed the possibilities of health insurance: the social system, the workplace, and more. The interconnectedness of numerous organizational parts of administration is challenged.

Conclusions

The need for change was a common statement across almost all participants in this study. Some expressed a vague feeling of the need to change, whilst others had examples or case studies proving that change is possible. Most suggested small scale changes or proposed modifications of existing structures. The complexity of the Swiss system hampers understanding, and makes it difficult to gain a global view of the driving forces. This renders change difficult. An in depth-analyses of the health care system and possible ways to implement a collaborative, multi-sectoral, inter-disciplinary cancer system in relation to the unique socioeconomic and political characteristics of Switzerland is an important next step.

Abbreviations

APN: Advanced Practice Nurse

SNC: National Cancer Strategy (Stratégie Nationale contre le Cancer)

Declarations

Ethics approval and consent to participate

The local ethics committee « Commission cantonale d'éthique de la recherche CCER – HUG » ruled that no formal ethics approval was required in this particular case. Written informed consent was obtained from all participants.

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests

None

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Authors' contributions

ML designed, developed and conducted the research studies including interviews, provided critical analysis of the research paper as well as co-wrote the research paper.

BB designed, developed and conducted the research studies, provided critical analysis of the research paper and had a role in writing of the paper.

All authors read and approved the final manuscript.

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