Improved access and reduced mortality

– it is time to escalate the fight against cancer!

A summary of the final report of Cancerkommissionen, All.Can Sweden.

Cancerkommissionen
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“Swedish National Cancer Plan 2020”

Improved access and reduced mortality – it is time to escalate the fight against cancer!

The fight against cancer has to be intensified. Despite all the recent improvements, more than one in three cancer patients die within five years. Even if the share of survivors has increased, this figure serves as a reminder of how much there is yet to do. Sweden ought to follow the likes of Denmark and Norway and adopt a National Cancer Plan in order to provide this onset with strength and structure.

There is a need for new research breakthroughs and a better functioning healthcare system in order to cure more people. According to the Cancer Commission, it is fully realistic to achieve changes in the healthcare system through the use of correct measures. Increased regional and national coordination holds great potential, not least in the area of IT. Much can also be done to improve research outcomes – one thought-provoking figure is that only one in a hundred cancer patients is involved in research projects. More efficient preventive efforts are needed to reduce cancer rates. The goal has to be that the current prognosis – which states that the number of new cancer cases in Sweden will go up to 100,000 per year – should never be allowed to come true.

Progress made in the healthcare system has created a new healthcare setting. For an increasing number of people, cancer is no longer a deadly, but rather a chronic, disease. Physical and mental difficulties often remain even when the tumour is gone. The cancer plan has to take into account the new demands on rehabilitation access and sometimes on both primary and home care. Today, the psychosocial efforts are often lacking, both during the time of illness as well as thereafter.

The main problem of the Swedish healthcare system is not money – but organisation

The Cancer Commission has attempted to gain an understanding of the situation in 1) the Swedish cancer care, 2) the cancer preventive work, 3) the cancer rehabilitation and 4) the cancer research. One observation on a general level is that the lack of resources is not the most conspicuous problem. In many areas, the resources are considerable and have increased over time. Healthcare spending in Sweden amounts to about 8-9 percent of GDP and this figure hasn’t changed much over time. The GDP growth, however, has been excellent, meaning that the resources have grown significantly. Practically speaking, almost all employment categories within the Swedish healthcare system have more employees now than a couple of years ago, even when the population growth is taken into account. For example, the number of working doctors in Sweden has increased by 66 percent in the last two decades. Moreover, the number of nurses is higher than it has ever been before.

The Swedish healthcare system has, since many years, been ranked among the top in international healthcare quality measurements, and in some instances, this also includes the cancer care. But among fantastic achievements by healthcare personnel and good healthcare outcomes, the Commission has also identified a number of shortcomings. And if a lack of financial resources is not the main problem, only one explanation remains: how these resources are used.

We see great weaknesses in the organisation of the healthcare system, that is, when it comes to leadership, knowledge management, IT, patient involvement etcetera. We believe that our suggestions – joint, national IT standards and a more rational governance being the most important ones – free up considerable resources which may be used for other matters. These may include higher salaries for surgical nurses, more research projects, not least in a clinical environment, and more advanced equipment.

Among the problems we have noted, the following may be emphasised. The access to healthcare is lacking – waiting times and postponed surgeries remain sources of great frustration. The knowledge management doesn't function well enough – in a time when new research results and other important discoveries appear non-stop, there must be a system in place which to a greater extent secures that healthcare personnel are up to speed.

There is also a complexity in that healthcare personnel sometimes haven't had the opportunity to gain the necessary experience required to minimise the risk for complications and mistreatments. It should also be noted that there are cancer types where other countries reach better treatment outcomes than Sweden. Judging by the statistics, it would seem that many other countries are better at treating metastatic cancer, i.e. instances where the primary tumour has created metastases and prognosis for treatment is considerably reduced. Many patients find the psychosocial treatment during the time of illness to be unsatisfactory. The need for rehabilitation after the initial phase of illness is much greater than its availability.

The above-mentioned factors are factors which also contribute to inequality within the healthcare system. Those who are able to – and in some cases also those who can afford to – find their way to clinics where these problems are handled successfully receive a better care than those who can't.

Some of our suggestions, mainly those involving large projects within the areas of rehabilitation and psychosocial caretaking as well as more research, cost money. We are of the opinion that they, to a large extent, are funded within the report's framework. If it, contrary to expectation, would turn out that the increased efficiency we promote does not free up sufficient financial means fast enough, the necessary resources should be more than covered by the new, large healthcare initiatives presented by the current government and the political opposition in the last year. As for allocating more resources to research, it should also be noted that a new government bill focused on research is planned for 2020. Earlier such bills have always, ever since they were first presented in the 1970s, included increased resources and we argue that so should be the case this time as well.

A National Cancer Plan to sharpen the fight against cancer

The Commission suggests that Sweden adopts a National Cancer Plan 2020. Such a plan would be a national commitment. It would be approved by the parliament and take the opinions of caregivers and other key actors into account.

The purpose is to make the fight against cancer more efficient and synchronised. The plan should include clear goals; such as an increase of five-year survival rates from today's 65 percent to at least 75 percent; that the number of people getting cancer should be significantly smaller than the current prognosis; and that the number of people being offered rehabilitation after the initial time of illness increases significantly within the time scope of the National Cancer Plan, so that it, in a few years, corresponds to the need. There should also be targets for shorter healthcare queues and reduced waiting times, as well as for the percentage of patients who are satisfied with the psychosocial support during the time of illness. In the plan, it should be specified which levels and authorities who hold the main responsibility for ensuring that each target is met, as well as a plan for how these targets should be followed up.

Increased national and regional involvement within the area of cancer

It is clear that increased regional and national coordination within the cancer area would improve the Swedish cancer care, as well as making access to it more equal.

We are convinced that, even if the main responsibility currently falls on the regions – and we are aware that the autonomy of the municipalities is rooted in the four basic laws of Sweden (similar to the constitutions of other countries) – that the state and the regions should be able to reach agreements enabling a more efficient structure.

The six regional cancer centres (RCC) and the national group coordinating them, constitute an embryo of the organisation needed. This structure should be made permanent and given a degree of autonomy and integrity so that decisions, including those that in the short perspective go against the will of a single region, will be accepted and followed. A technical solution that is not in conflict with the regions' autonomy, may be that the regions create local federations ("kommunalförbund") for the task.

National IT standards for all healthcare and medical R&D

IT services in the Swedish healthcare system are severely lacking. Systems which do not communicate with each other are a source of excess work and frustration. Compared to how it could work, today's situation is nothing but catastrophic. The suggestions presented by the Cancer Commission in this area are not limited to the cancer area but cover all areas of healthcare and medically related research in Sweden. The state has to, preferably through conditional state grants, but as a last resort also through legislation, push through national standards for the IT systems of the healthcare system and the medical research. This should, among other things, include the Swedish Quality Registries, blood and tissue banks, updated patient data. Privacy and protection of personal integrity must be of utmost priority in this process. The legal insecurity currently in place in many organisations through decisions by the Swedish Data Protection Authority as well as court rulings, and which may be increased by the GDPR, must be handled. In the short term this has to happen with the help of central recommendations for how the current laws should be interpreted, but in the long term – but as soon as possible – through the issuing of a modernised Patient Data Act.

It is obvious that digitalisation will have a revolutionising impact on the Swedish healthcare system. But our suggestion does not primarily focus on the future, but rather at the current situation. It aims to eliminate the frustrating daily problems within the healthcare system, quality control and research; that in an astounding manner has been allowed to steal time from healthcare personnel and prevent the utilisation of existent, but inaccessible, research data. As for the digitalised care methods that are now being tested or are waiting around the corner, we also strongly believe in their potential, not least when it comes to involving the patients in their own healthcare. It should also be noted that the introduction of new, digitalised care models will be made significantly easier if the IT systems are compatible.

And we are in a hurry. Most regions are about to introduce new healthcare information systems. Many attempts at coordination have failed. This cannot continue.

Summary

- The Swedish parliament should adopt a Swedish National Cancer Plan 2020, after discussions with caregivers, patient advocacy groups and other stakeholders. The plan should include ambitious targets and a clear distribution of responsibilities.
- A distinct purpose of the plan is to establish a stronger regional and national coordination of Swedish cancer care. The system with six RCCs and one national coordination group should be made permanent and reinforced. This requires commitment on a national level.
- A possible way forward to reinforce the RCCs is for the regions to convert them into local federations ("kommunalförbund").
- National commitment is just as necessary to establish joint IT standards for all healthcare as well as medical research and development. The state should provide financial means during a limited period of time to stimulate the development. If the responsible authorities fail to fulfil the demands they should receive reduced state grants. As a last resort legislation may be considered in order to solve this acute problem, which not only constitutes a waste of healthcare personnel's time, but also threatens patient security.
- Even if the registration of patient data is simplified by joint IT standards, there is a need for a review of the demands on registration in patients' medical records so that the total registration burden is reduced.
- The Swedish Patient Data Act should be reviewed and updated from today's technical reality.
- The Public Health Agency of Sweden should be tasked with intensifying the information campaigns regarding smoking, excess sun exposure, overweight and a sedentary lifestyle. It may be that some cancer types are caused by hereditary factors or by environmental factors which we cannot affect as individuals. But according to the World Health Organization (WHO), a third of all cancer cases may be prevented through lifestyle changes. These health recommendations also mean that there is less comorbidity among cancer patients when they do get cancer, which in turn improves the conditions for successful cancer treatment.
- Introduce a tobacco display ban in the Swedish retail industry.
- Consider a successive increase of the excise tax on cigarettes. The tax increase should have the objective of successively making cigarettes significantly more expensive relative to consumer price index (CPI).
- Introduce HPV vaccination of boys in the Swedish Immunisation Programme for Children.
- Increase the financial resources to medical research significantly in the next government bill on research.
- Establish, with the help of the increased resources from the above-mentioned government bill on research, 1-3 well-financed Comprehensive Cancer Centres (CCC) in Sweden. One condition for national support should be that the CCC, regardless of how many they are, create a strong national culture of coordination so that the advantages of a large population basis, easy access to national data bases etcetera is secured.
- Establish more combined employment positions so that all clinically active healthcare personnel gain increased possibilities to conduct research.
- Resources for rehabilitation should be dimensioned so that all patients may be offered relevant efforts in accordance with the national healthcare programmes.
- Improve the psychosocial support for patients and their friends and family, for example through securing access to contact nurses/patient navigators, psychologists and welfare officers.
- Enable more research in order to examine which rehabilitation efforts are the most relevant for different patient groups.
- Examine a broader introduction of flexible sick leave for patients in cancer treatment according to the model piloted in Region Västra Götaland.

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