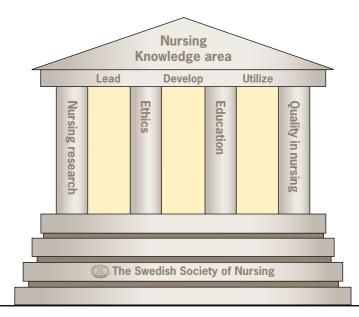


# EQUITY IN CARE AND HEALTH



The Swedish Society of Nursing is the professional organisation for registered nurses and nursing students. It is a non-profit organisation that represents the nursing areas of expertise. Tasks in the organisation is based on four ground pillars: research, ethics, education and quality improvement. www.swenurse.se



#### **Production**

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#### **PREFACE**

The Swedish Society of Nursing represents the nursing profession, nursing science and research. With this strategy, we make a contribution to all registered nurses, in all areas, who work for equity in care and health for the whole population.

This new strategy is based on the Swedish Society of Nursing's first strategy concerning health promotion in nursing, published in 2008. The first strategy clarified health promotion in nursing and demonstrated how knowledge about health and health promoting activities can be used in clinical practice. In 2010, the Society published the document *Everyone has the Right to Healthcare – a guide to human rights in everyday healthcare*. Both these documents contain facts which can be found, updated, in this strategy for equity in care and health.

The board of The Swedish Society of Nursing gave the project group the task of compiling a document that reflects the role of registered nurses and hospital teams in promoting health. The document should also include results from research about inequities in care and discrepancies in health. A close look at the literature reveals that this research area is incoherent and that the significance of nursing in this context is not sufficiently recognised. Although health promotive nursing and equity in care are areas of research that needs to be further developed, we choose to highlight and describe a number of good examples that can be inspirational.

We live in a country that is prosperous, but despite this there are considerable differences in health among various groups in Sweden, and as the current government has targeted closing these gaps within a generation, the Swedish Society of Nursing wishes to take part and make a difference.

Warmest thanks to Professor Ania Willman who did the groundwork for this strategy. Thanks also to Yayoi Kusama for giving us permission to use her art and for good cooperation.

#### **Ami Hommel**

President of the Swedish Society of Nursing



Colourbox

#### **The UN Universal Declaration**

of Human Rights states that all human beings are born free and equal in dignity and rights, that everyone has the right to life, liberty and security of person, and the right to a standard of living adequate for health and wellbeing including medical care. Equity in care is closely linked to human rights.

The UN Convention on the Rights of the Child establishes that all children and young people under the age of 18 years have the same rights to life and development, a secure childhood and protection against abuse and harm. The views of the child must be heard and respected in matters that concern his or her rights. The best interests of the child must always come first.

**The UN Convention** on the Elimination of All Forms of Discrimination against Women states that women have the same rights as men.

The UN Convention on the Rights of Persons with Disabilities aims to reinforce the protection of human rights of persons with disabilities already provided by other conventions. It focuses on non-discrimination and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their political, financial, social and cultural rights.

# **INEQUITY IN CARE**

There are unmotivated differences in the Swedish public medical service. for example between socioeconomic groups, geographic areas, sex and gender despite the fact that guidelines and documents that steer the service demand it to be equitable. Swedish care is inequitable. The differences are significant and constant and there are some considerable regional differences. The inequities are apparent even if the examples vary. Inequitable care is, for example, that men who suffer from strokes are treated at stroke units more often than women, or that women and men with low education levels die more often from myocardial infarction or stroke than those who have a high level of education. The National Board of Health and Welfare (Socialstyrelsen) and The Swedish Association of Local Authorities and Regions (SA-LAR) reported 2012 that there are differences in, for example, the treatment of kidney diseases and osteoporosis. In a national evaluation for 2013, it was shown that every 14th woman in the county council Jämtland suffering from breast cancer needed re-operating because of complications, while in the county council Blekinge only one woman in 100 needed to be re-operated.

Equitable healthcare and public medical service means that all people are offered care according to their needs, on equal terms and with good treatment, regardless of sex, gender, sexual orientation, ethnicity, religion or other beliefs, disability, age, place of residence, education or economy. The concept of equity includes equality. Equality is about the relationship between the sexes while equity implies individual's and group's equal rights.

In 2014 the annual comparison between OECD countries showed that Sweden is ahead of most countries regarding life expectancy and low infant mortality. Sweden also demonstrate better results than most countries concerning survivors from cancer diseases and cardiovascular diseases. Compared to other countries, Sweden has many physicians, few patient visits per physician, short length of stay and few beds in hospitals (Commission for equity in care, 2015; Commission for equity in health, 2016). At the same time, The Swedish Agency for Health and Care Services Analysis (2014a) shows that Swedish patients seldom receive information about treatment options and that Swedish care is rated last, of the countries monitored, at discussing drugs and their side effects with patients. Patients experience that physicians and other healthcare professionals do not take responsibility for coordinating contacts with other parts of the healthcare system, especially after hospital discharge.

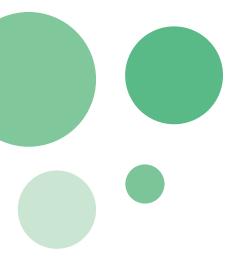


The Commission for equity in care (2015) considers that inequity in care is especially serious in a country like Sweden, which has promised its people that the individual will be offered high-quality care that relates to his or her needs and that it shall be given with reference to research and best practice. The point of departure for this criticism is the introductory text of the Health and Medical Service Act (1982:763) that states that the aim of the Swedish healthcare and public medical service is good health and care on equitable terms for the entire population. The Commission states that equity in care should not be limited to what it is obliged to offer, but must also incorporate adjustments to the different outcomes of care. If this is not done, inequity in care will eventually pose a threat to the whole system.

The United Nations (UN) declarations of human rights are laid down in 30 different articles and declare among other things that all humans are born

Equity in care is closely linked to human rights.

It is above all in the encounter between patient and carer that inequalities appear.



free and equal and have the right to life, liberty and security of person, and the right to a standard of living adequate for health and wellbeing, including medical care. Equity in care is closely linked to human rights.

The Patients' Act (2014:821) came into force in 2015 and aims to clarify and reinforce the role of patients in healthcare and public medical service. According to this Act, the care, when possible, should be planned and implemented together with the patient. Although there is much that indicates that increased understanding of the patient's own experiences and context makes care more appropriate, it cannot be said that the care of today, in every given situation, considers individual health needs.

The Swedish Agency for Health and Care Services Analysis (2014b) notes that it is above all in the encounter between patient and carer that inequalities appear. The Agency stresses three explanatory mechanisms; that the healthcare sector is unable to adapt to patients' various personalities and backgrounds, that carers' preconceived ideas about, for example, age and sex influence the way they act and that the norms and values of carers create behaviours they are unaware of.

Another threat to equity in care is the inconsistent dissemination and implementation of evidence-based methods. Coordination of national actors' undertakings is needed for efficient implementation and likewise to adapt knowledge to local conditions. There are various examples of difficulties in applying knowledge-based methods, one example tells how hard it is to make use of psychotherapeutic methods to treat anxiety and depression when there is a lack of psychotherapeutics in many regions. Another example is that under-staffing together with a lack of specialist nurses has devastating consequences. This concerns mainly patients who are exposed to several risks including cancelled operations, incorrect treatments or that they receive insufficient good and safe nursing. The lack of specialist nurses is also an obstacle for the implementation of evidence-based methods because it is they who have the cutting-edge competence.

# **INEQUITY IN HEALTH**

The Public Health Agency of Sweden shows in its 2016 report that public health in Sweden is developing positively, life expectancy of the population continues to increase and differences between the sexes are decreasing. The flip-side is that there are health differences between groups of people, and these differences are increasing. Health, and differences in health, is influenced by people's living conditions and lifestyles. When the population is graded according to levels of education it is those with the least education that suffer from the worst health, this is often called the social gradient. For example, there are greater differences in life expectancy between persons with low levels of education respectively high level of education than there are between women and men. As income distribution continues to increase, we also see increased differences between various education groups regarding economic standard. The development for women with low level of education is especially weak (The Public Health Agency, 2016).

The government wishes to balance the socioeconomic differences, and the aim is to bridge the gap within one generation. Hence, it will be necessary to adopt a holistic approach to the population's health, which involves more actors than those of healthcare and public medical service. Not just the government has come to this conclusion. Several municipalities and regions are focusing on people's health as never before. In the city of Malmö, for example, the whole administration has equity in health as a goal and in Region Örebro and in Botkyrka similar work is being carried out.

The development of healthier lifestyles over the past ten years is in the main positive, but there are considerable socioeconomic factors that differ, for example education, economy and work. The level of education in Sweden continues to rise. In general, women's education is higher than men's and this difference is increasing. There is a clear connection between higher levels of education and better health. The differences in life expectancy between groups with varying educational backgrounds has increased over the past few decades. The last five-year period saw no increase in life expectancy either for women or men with only primary school education, while those with secondary or university education saw their life expectancy continue to grow. Women with only primary school education have the least favourable development (The Commission for equity in health, 2016).

Life expectancy is influenced by living conditions. Income levels and economic standard affects the chances of enjoying good health, and prospe-

There is a clear connection between higher levels of education and good health.

Levels of income and standard of living have an impact on health, and wealthy individuals are healthier and live longer that those less fortunate.

WHO lists six areas where measures need to be taken in order to lessen inequity in health:

# 1. Children's early development

Give every child the best start in life.

#### 2. Education

Make it possible for children, adolescents and adults to maximise their potential and gain control over their lives.

#### 3. Work

Create equitable working conditions for all people.

# 4. Make it possible for all people to enjoy a healthy standard of living

#### 5. The environment

Create and develop healthy and sustainable societies.

#### 6. Healthcare

Reinforce the role and significance of preventive care in decreasing diseases.

WHO (2014) Review of social determinants and the health divide in the WHO European Region: www.euro.who.net

rous individuals are healthier and live longer than those with scarce means. The standard of living continues to improve while the differences between groups increase. Persons living in relative poverty, an economic standard that is under 60 percent of the amount of income needed to maintain the average standard of living in the society in which they live, has increased from 8 percent in 2004 to 13 percent in 2014. It can also be seen that the risks of marginalisation and ill health increase for those living in relative poverty. Development of economic standards are very slow for women with low levels of education. III health is higher among the unemployed than among those that are working. In the year 2015, 25 percent of women and 17 percent of men in the group of people with only primary education were unemployed, and unemployment in this group increased the most from the year 2002 to 2015. In Sweden unemployment rates is significantly higher for young people than for older people (The Public Health Agency, 2016). The ill health and premature deaths which represent inequality between for example education groups, is not just about human suffering and lost years of life, it is also about direct costs linked to ill health, such as loss of production, healthcare and sick leave. Because social differences in health are mostly caused by health issues that are treatable, there is, apart from the moral aspect, also a social perspective of sustainability (The Commission for equity in health, 2016).

Women with disabilities and breast cancer are twice as likely to die as other patients with breast cancer, partly because they are diagnosed at a later stage.

(National Board of Health and Welfare, 2013)

#### Cardiovascular diseases and cancer

Non-communicable diseases (NCD) comprise the majority of premature deaths worldwide, about 35 of 53 million deaths in 2010. The number is expected to increase to 55 million premature deaths by the year 2030. In Sweden NCDs are behind 90 percent of all deaths. Four categories of diseases are involved in these high death rates: cardiovascular diseases, cancer diseases, diabetes and chronic/severe lung diseases. The common risk factors for these categories are mainly: tobacco, unhealthy alcohol and food habits and insufficient physical activity. The most common causes of death in Sweden are cardiovascular diseases and cancer. Mortality in cardiovascular diseases has decreased significantly over the past decades and sickness and death nowadays occur at more advanced ages. Cardiovascular diseases are influenced by factors such as unemployment, inactive leisure time, obesity and tobacco. In all age groups the risk to have a heart attack is higher for those with a lower level of education. In Sweden, the risk of suffering a stroke has continued to decrease since 2005. The risk increases

with age and, in the group of people with low education, the risk is higher at any age (The Public Health Agency of Sweden, 2016).

While cardiovascular diseases decrease, cancer has grown in significance and nowadays every third person is expected to be diagnosed with cancer during their lifetime. Every year, about 22.000 people die of cancer in Sweden, making cancer diseases the most common cause of death for people under the age of 80. Cancer mortality has somewhat decreased, despite the increase of diagnoses. Nowadays, diagnoses are often made at an early stage, thus rendering better prognoses. The risk of dying in cancer increases with age. Eating habits are significant for the disease, as are tobacco, alcohol, physical inactivity and being exposed to the sun (The Public Health Agency of Sweden, 2016).

According to a report from the Swedish Cancer Society (2012), a patient's survival after being diagnosed with cancer is linked to his or her socioeconomic status. An investigation carried out among all cancer sufferers to derive how many people survive five years after being diagnosed, showed a very clear discrepancy of survival between those with the highest and those with the lowest socioeconomic situation. During the past 15–20 years, survival has increased for all socioeconomic groups, but the differences between the groups are consistent. Innovations and improvements of quality are not equally shared (The Public Health Agency of Sweden, 2016). According to a report from Socialstyrelsen (2013) concerning an evaluation of the three most common forms of cancer in Sweden, patients with bowel and rectal cancer and low levels of education do not receive, to the same extent as others, the diagnosis and treatment recommended. Other signs of inequity between education groups show that those with low level of education and rectal cancer, are more often re-operated because of complications, than those with higher education. Similar tendencies are observed regarding differences in treatment of breast and prostate cancer. Nor do disabled persons receive equitable care. Women with disabilities are twice as likely to die from breast cancer in comparison to other patients with breast cancer, partly due to being diagnosed at a later stage (Socialstyrelsen, 2013).

#### Persistent mental illness

Persons suffering from persistent mental illness are identified as a risk group in need of somatic care. Their dual diagnoses challenge the healthcare's and the public medical service's ability to recognise risks of ill health and to take promotive health measures in time. Persons with mental illness often suffer

Persons suffering from mental illness often have a reduced cognitive function that can influence their ability to appreciate, understand and use information about their health.



Dots Obsession 2015 Installation view: YAYOI KUSAMA IN INFINITY at Louisiana Museum of Modern art.

#### Kusama biography

Yayoi Kusama (b. 1929) is a world renowned Japanese avant-garde sculptor, painter and novelist. She has exhibited her work all around the world in some of the most famous museums including Moderna Museet in Stockholm, Museum of Modern Art in New York and Mori Art Museum in Tokyo. Kusama has expressed her artistic vision in paintings, collages, installations and performances. Kusama's art is an expression of her life and especially the hallucinations only she can see. She then translates her hallucinations into some of her artworks in different genres.

from a reduced cognitive function that can influence their ability to assimilate, understand and use information about their health. Thus, their need of somatic care is greater than that of other groups.

People with mental disorders have, to a higher extent than the population in general, lifestyle risks and habits that lead to ill health, for example smoking, unhealthy eating habits and lack of physical activity or addiction to drugs. To persons suffering from schizophrenia, lack of energy and motivation are typical symptoms that might be part of the illness. These groups can thus find it difficult to accept advice and information about seeking care for somatic problems. Added to this, there are many necessary anti-psychotic drugs with side effects that increase the risk of cardiovascular diseases, for example gaining weight and increased levels of blood fats and sugar. The mortality among persons with mental disorders are higher than in the population in general. Especially vulnerable are psychotic persons who also suffer from coronary artery

disease. One reason could be their low collection of prescriptions for secondary preventive drugs and that they seldom undergo X-rays of the coronary arteries when suffering from coronary thrombosis (Socialstyrelsen, 2014).

#### Young people and mental illness

Mental illness is increasing among young people while it is decreasing among older people. Progressively more young people who report mental problems such as anxiety and nervousness, are treated as in or out patients at psychiatric clinics and are prescribed psychopharmacological drugs. Depression and anxiety are the most common problems. The most significant increase of mental illness is for 15-year-old girls (57 percent) and boys (31 percent), twice as many as at the onset of registration in the 1980s. For both women and men, problems of anxiety and nervousness are more common in the youngest age group, 16–29 years old. Suicide is more common among men and persons 45 years and over, than among younger people. Suicide is decreasing overall, except for the age group 15–24 years where it increases every year, especially among boys and young men. In this group, persons who undergo hospital treatment for self-harm is common compared to other age groups (Public Health Agency of Sweden, 2016).

Next of kin's experiences with mental illness show that the illness has great impact both on the person who is ill and on the family. The fact that mental illness is considerable among young adults often results in substantial responsibility for their next of kin to support friends or families in situations of, e.g., world-weariness, threat of suicide, depression and anxiety. Friends and acquaintances who support and take responsibility for the sick young person often need help themselves.

#### **Habits of life**

Healthy lifestyle options such as non-smoking, moderate use of alcohol, physical activity and good eating habits promote health and prevent illness and sickliness. Healthy habits of life are influenced by where you live, levels of education, economic and social situation. Although 60 percent of all women and men in Sweden today, are physically active on a regular basis, those who are inactive in their leisure time still comprise 13–15 percent. Inactive leisure time means exercising less than two hours a week. This is more common among older women (65–84 years) and people with low levels of education.

**Increasing numbers** of young people who report symptoms such as nervousness and anxiety are treated at psychiatric clinics as outpatients or inpatients and prescribed psychotropic drugs.

Children need at least one hour of physical activity per day. This gives an improved state of health, strengthens the muscles and the skeleton, decreases high blood fats, heightens self-esteem and improves school results.

Healthier diets, or good eating habits, mean eating more fruit and vegetables, and less salt, sugar, saturated and trans fats. Not eating enough fruit and vegetables is a risk factor for high burden of disease (Public Health Agency, 2016).

High BMI is a risk factor for several illnesses including diabetes type 2, cardiovascular diseases, high blood pressure and cancer. Overweight imply a BMI between 25 and 30, and obesity a BMI over 30. In 2015 the proportion of overweight persons was 29 percent for women and 42 percent for men. The number of persons with obesity has increased. Mostly for people between the ages of 45–84 years. Obesity is more common among people with low education levels (Public Health Agency of Sweden, 2016). Being overweight and obese are complicated conditions with biological, social and environmental determinants (Butland et al, 2007).

Overweight and obesity among children has substantially increased over the past 25 years, but there are no current national data on children's obesity. Numbers from 2011 showed that 17 percent of Swedish children between the ages of 7 to 9 years were overweight and this includes 3 percent who were obese (Sjoberg et al, 2011). Regional data from the county council Skåne in 2011, showed that 10,1 percent of four-year-olds were overweight, including 2,3 percent who were obese (Region Skåne, 2011). In comparison with other European countries these numbers are relatively low, but, despite this, should be highlighted. Current research shows that work to prevent overweight is not prioritised in the Swedish child healthcare because child healthcare nurses consider they lack knowledge, guidelines and resources (Isma, 2016).

The importance of preventing overweight and obesity as early as possible is well known as problems can accelerate in adult life. An organisation of professionals promoting physical activities (YFA) recommends that children need at least one hour of physical activity a day. This gives an improved state of health, strengthens the muscles and the skeleton, decreases high blood fats, heightens self-esteem and improves school results. Physical activity at school is particularly important to those children who are not otherwise active (YFA,2016).

Both the use of tobacco and the consumption of alcohol are decreasing in the population, despite this 14 percent are calculated to have risky alcohol habits. The number of people who smoke or use snuff daily has decreased over the past ten years in Sweden, but according to Socialstyrelsen (2013), the increasing differences in mortality and length of life between the education groups, especially for women, is explained mainly by increased mortality caused by illnesses connected to smoking. The monthly binge consumption of alcohol has decreased in Sweden and this is particularly clear as a trend





among young people (16–19 years) and adolescents, but for older people (65–84 years) it has increased. Alcohol related causes of death are most common among persons with low education levels and uncommon among those with higher education (Public Health Agency, 2016).

## Older people's complex health issues

Many elderly are well and enjoy good health up to advanced old age, but in order to minimise personal suffering and social costs, it is important that groups who are at risk for sickness and ill health are identified early on. In today's healthcare and public medical service system, these risk groups are identified far too late, often when sickness and frailty have already occurred.

Frail elderly often suffers from several complex diseases and health

Better care for frail elderly includes continuity in their contacts with the healthcare system. Persons with severe illnesses and the elderly with complicated health issues experience the greatest difficulties in finding good care in the current system. problems simultaneously. Even if care is supposed to be accessible to older people, and no one should be refused care or medical treatment due to age, there are many examples of age discrimination. There is a risk that older people's symptoms are treated instead of the causes of the problems.

Methods of treatment can vary per age (The Cancer Society, 2012). Social-styrelsen (2013) found that older women more frequently than men of the same age are prescribed drugs that can cause confusion and falls. Few older persons are included in clinical studies and this can lead to under-treatment or wrong treatment, among other things because different treatments and drugs for older people are insufficiently tested. One example of age discriminating under-treatment is that only about every tenth 90-year-old patient suffering from atrial fibrillation is prescribed warfarin therapy. If all who need it were given this therapy the number of cases of strokes would decrease by 5.000 a year in Sweden (SBU, 2013a).

Persons with severe illnesses and older people with complicated health issues experience the greatest difficulties in finding good healthcare in the current public healthcare system. This system can be described as a reception-based system where a person with severe, developed and recurring problems is forced to visit many different clinics and healthcare providers to achieve the necessary treatment. Better care for frail elderly includes continuity in their contacts with the healthcare system (SBU, 2013b).

It has been shown before that Swedish emergency departments have faulty routines and competence of care for older people. Under-staffing, insufficient competence in the care of older people, overcrowding of the wards and an increase of frail older people, lead to long queues at emergency departments. These queues have been shown to be of the detriment to frail elderly people. Emergency care is badly adapted to meet the needs of frail elderly. The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU, 2013b) has reviewed existing research and found that team-based structured care of older people results in improved abilities and increased opportunities for them to remain in their homes after hospital discharge from emergency wards. Despite flaws in the scientific basis, it is crucial that collaboration in the care of the elderly is reformed. Several studies have shown positive results of district nurses offering home visits to 70–75-year-old people with overall god health, for example Sherman (2012) shows that health deteriorates at a lower rate when older people were visited once for a health talk. Several health problems within the frame of a district nurse's work were identified, and could thus be addressed.



The contribution from next of kin

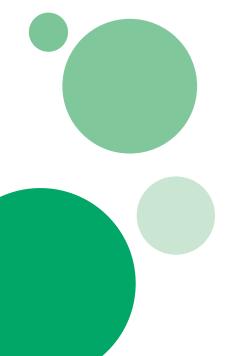
Next of kin take increasingly more responsibility in healthcare, for example in areas such as the care of persons with cancer diseases, stroke or mental health illness.

Many next of kin of persons with severe mental health issues feel they are burdened in several parts of their lives. A European study shows that a third of those close to a patient feel burdened in three of the following five areas of life: social, emotional, physical, relational and financial. They are especially worried about the future and the long-term situation of their loved-one, i.e. the person with mental ill health issues (Vermeulen et al, 2015).

Next of kin, who are children, are especially vulnerable for many reasons. Partly because they are dependent on the person who is suffering from disease and partly because they may find it more difficult to understand

A person's next of kin are important to the national welfare as they balance the costs of healthcare.

Over the past three decades, society's activities for older people have decreased.



what is happening, and the reasons. Children and adolescents can, in these situations, risk being influenced negatively by their own and the grown-up person's anxiety, by changes in daily routines, and the child is sometimes obliged to take unreasonable responsibility, perhaps combined with lack of care and painful experiences. It is important to highlight children's needs and give the support needed as this can improve the situation both here and now and prevent negative consequences later on (Socialstyrelsen, 2013b).

Many older people live at home until they reach advanced age. The need for care increases while at the same time there are fewer places available at hospitals and care facilities. People are discharged early from hospitals because the beds are needed. Over the past three decades, society's activities for older people have decreased.

In Sweden, from 2001 to 2012, every fourth place at homes for the elderly disappeared, altogether about 30.000 places. This loss of public health and social care has been replaced mainly by the input of patients' relatives and next of kin. There is a definite class structure to this input. Care by relatives and next of kin is considerably more common and comprehensive among people with a low level of education. Care purchased privately is more common among older people with higher education. About 360.000 people of the working age population, help an elderly, sick or disabled person daily or several times a week. And 80.000 - 100.000 people have reduced their working hours or have stopped working entirely to care for somebody. Every fifth middle-aged woman, and slightly fewer men, help a family member or friend who, due to age, illness or disability, need assistance at least once a week. It is more common for women who are carers to be off the labour market than it is for women who are not carers. This is the case mainly for women with low education level. There is no such correlation for men (Szebehely & Ulmanan, 2012).

Hence, the contribution from next of kin comprises the bulk of the help and assistance given to Sweden's elderly population who live at home and suffer from one or several severe diseases. Calculated in time, it is mainly older people who help with caring, usually for a partner at home. This contribution is significant to national welfare as it balances the costs of care. While the focus on care of the elderly shifts from hospitals and institutions to home care, it is reasonable to assume that the contribution from next of kin will not decrease.

A great number of older persons, who need assistance from next of kin, suffer from dementia. More than half of them live, and are cared for, at home. The next of kin, who assist, and at a later stage, nurse a relative, need quality support so that they themselves do not become ill. Research shows that the burden many families and friends carry lightens when they receive support through education programmes, which can also make an impact on depressed carers who nurse a person with dementia at home (SBU, 2015).

#### LGBTQ persons' care and health

People who break norms by living in same sex relationships, or whose sexual orientation or gender expression does not coincide with the person's biological, social or legal gender, are named LGBTQ<sup>1</sup>.

This norm-breaking position has a negative effect on a person's health and health conditions for life (Public Health Agency, 2014; 2015).

LGBTQ persons are found in all areas of healthcare and public medical service, for example the nuclear family at maternity and birth units, the teenage boy at the youth clinic trying to find himself, his sexuality and opportunities to express it, or at the oncology centre where persons with breast or prostate cancer wonder how their sexual ability and practice are influenced by disease and treatment. In geriatric care and nursing homes there are also LGBTQ persons, for example Karin and Birgitta (two women) who wonder whether they can share a room, or John who wonders how his HIV infection will influence the way he is treated by co-patients and staff.

The Public Health Agency (2014; 2015) has shown that even though most LGBTQ persons are well, there are groups within the group whose health is worse than that of heterosexual persons. Mental health in all groups is inferior compared to that of heterosexual persons which is reflected in a higher rate of suicidal thoughts in the LGBTQ group. This is often related to the minority stress they experience. Transgender persons feel, predominantly, that they cannot be themselves. There are those who have experienced discrimination and violence within the LGBTQ group. Especially lesbian and bisexual women describe lack of confidence in authorities, including healthcare and public medical service staff. Gay and bisexual men lack both emotional and practical support to a greater extent than heterosexual men. Use of tobacco is higher among gay and bisexual men, but women's consumption has decreased. Compared to heterosexual persons, alcohol intake is higher among LGBTQ persons.

In Sweden, transgender persons have been able to undergo treatment since the middle of the 1970s which means that the oldest among them are now over 90 years old. However, transgender persons still need a referral to psychiatric **Lesbian** and bisexual women, especially, report that they lack confidence in authorities, including nursing staff.

**Gay** and bisexual men miss both emotional and practical support more than heterosexual men.

<sup>&</sup>lt;sup>1</sup> LGBTQ is an overall term for lesbian, gay, bisexuell, transgender and queer persons.



There are many places all around the world where women, children and other vulnerable groups do not have the same rights as others. The concept of "treatment that cannot be deferred" is incompatible with the Code of ethics of health professionals. It is not medically applicable, jeopardizing patients' safety and leads to inequity in care.

care for help to match their sexual orientation with their body status. Knowledge about transgender persons and their needs is scarce in healthcare and public medical service and often it is the transgender person in need of care who educate the staff (The Public Health Agency of Sweden, 2016).

## Asylum seekers and undocumented immigrants

Everyone has the right to good healthcare, but not everyone receives care according to their needs. In many places around the world women, children, refugees and other vulnerable groups do not have the same rights as others. Therefore, the UN has worked very hard to create documents that sustain the protection of fundamental human rights, such as the right to a standard of living adequate for health and wellbeing, the right to avoid activities that

are detrimental to health, and the right to healthcare. Persons in need of care shall receive the care they need regardless of legal status. The UNs member states have also agreed on several conventions designed to protect especially vulnerable groups in society, for example women, children and persons with disabilities. These conventions apply to Sweden as well.

In a multicultural society, such as Sweden, healthcare and public medical service staff often meet patients with different ethnic backgrounds and culture that differs from their own. About 650.000 asylum seekers have reached Sweden in the past 16 years. In 2015, all together 163.000 persons applied for asylum in Sweden, 51.000 of these were from Syria. In the same year, 35.000 unaccompanied children arrived, most of them boys, and 66 percent were from Afghanistan.

Since, unaccompanied refugee children are short of income and education and often suffer from uncertain places of residence, physicians and registered nurses must take into consideration that these young people have an increased risk of sickness and ill health (Hirani et al, 2015).

Persons who flee have, to a somewhat lower extent than those born in this country, been in contact with a general practitioner (Thomas et al, 2007). Obstacles to refugees seeking contact with healthcare and public medical service can be: language, culture, sparse knowledge of health problems; ignorance of the system, financial and/or hinders of transport (Sheik-Mohammed et al, 2006). Female asylum seekers seem to be the most vulnerable group, a group that needs to be highlighted (Gerritsen et al, 2006).

Although the UNs declarations and conventions provide formidable legal protection for vulnerable groups, they are not always abided by. The conventions are meant to prompt political decisions and it is important that registered nurses and other professional groups live up to their ethical codes and work to oversee that the healthcare system lives up to these considerable demands. In Sweden, adults who are asylum seekers or undocumented immigrants have the right to "treatment that cannot be deferred". The Swedish Society of Nursing works together with many other professional, religious, trade unions, and humanitarian organisations to erase the concept "treatment that cannot be deferred" from the law because it is insufficient. The concept is incompatible with the ethical codes of health professionals, it is not medically applicable, risks jeopardizing patients' safety and leads to inequity in care. Registered nurses must promote an environment where human rights, values, customs and religious beliefs held by the individual, by families and by the public are respected.

The concept "treatment that cannot be defererred" is incompatible with the ethical codes of health professionals.



**Health-promotive** nursing care is about enhancing people's trust in their own capabilities.

#### Suitable outcomes

from the perspective of health-promotive care, are increased knowledge, changed values and attitudes, and experiences of capability and meaningfulness.

# HEALTH PROMOTION IN NURSING CARE

The point of departure for health promotion in nursing care is the belief that people are capable of health and wellbeing regardless of sickness and ill health. Health-promoting nursing stems from a humanistic view of the human being and focuses on understanding a person's lived experience in relation to health, sickness and suffering, instead of focusing on problems and diagnoses.

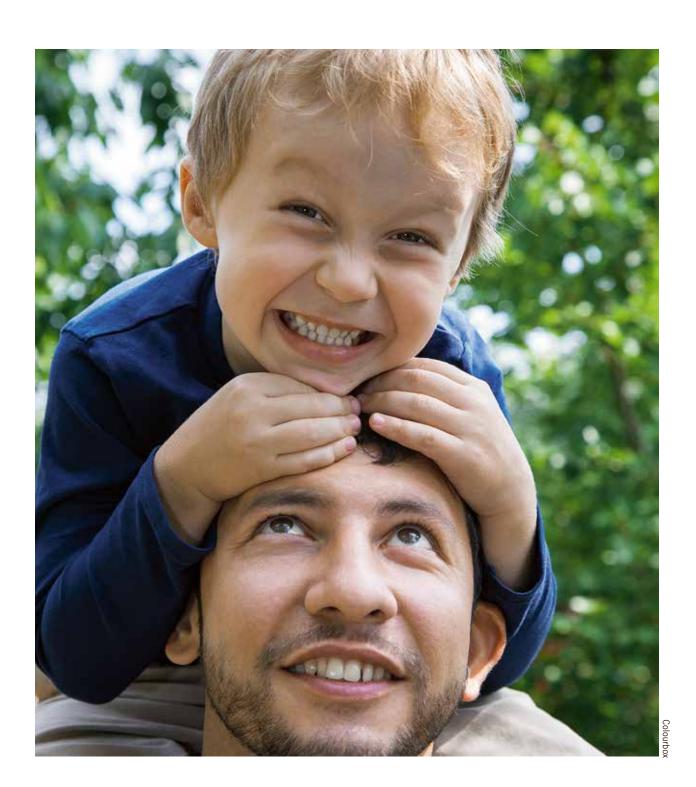
The foundation for activities in health-promoting nursing are dialogue, participation and equality, when encountering a person. Health-promoting nursing means that the carer confirms the person and their experience, focuses on the person's future, verbalises feelings and adapts support according to the person's capacity (Willman & Gustafsson, 2015).

Nursing seeks to achieve equitable and mutual collaboration with an aim to give the person/patient the opportunity to take part in decisions, to engage and to control. The patient is encountered an equal and capable person with the ability to make autonomous decisions. Equity in care facilitates for the person to participate in the planning of health-promotive self-care. The registered nurse's task is to give the patient opportunities to make sound decisions through dialogue, participation, individual planning, adequate information and knowledge. The registered nurse must support the patient's feeling of hope and motivation.

Nursing is mostly practiced at a personal level and consists of the two aspects, relationship and fact. The person in need of nursing requires for example support, guidance and active assistance with something (aspect of fact) and this something cannot be accomplished lightly, it must be delivered in a good encounter (aspect of relationship). The aim of nursing care is to promote health and wellbeing, prevent ill health and relieve suffering, and to work for a peaceful and worthy end to life for persons who are ill and dying, considering their cultural background, age, sex and social conditions. The aim is also to balance the power structure in the relationship so that the patient and next of kin can participate, feel confidence and experience respect (Swedish Society of Nursing, 2016).

Within the framework of person-centred nursing care, there must be an approach that entails openness towards the patient as a person, and what he or she wishes to convey. Person-centred care means allowing the patient to become a co-creator and partner in his or her own care and treatment.





A person-centred approach means listening to the patient's narrative, becoming conscious of the person's will, motives and resources. Fundamental to person-centred care is the person's narrative. It expresses a person's identity and by listening the staff contribute to the person's experience of wholeness and meaning. The task of the staff is, together with the person, and sometimes his or her next of kin, to form a personal health plan where needs and resources are identified in the person's narrative. The staff often have the job of encouraging and strengthening the remaining health resources of a severely ill person or someone with health problems. The healthplan is an agreement/contract formed in partnership with the patient and must be documented to secure person-centred care (Ekman, 2014).

When registered nurses work with health-promotive nursing, the nursing care is based on knowledge from nursing research, combined with medical and public health research and their own clinical experience, when boosting an individual's health. Apart from working at a personal level, registered nurses can also do health-promotive work at group and societal levels.

Although health-promoting activities in terms of strengthening the individual's capability and subjective experience of health have been noticed, the usual definition of health-promotive care is still from a perspective that focuses on prevention of sickness. From the perspective of health-promoting nursing care, knowledge, changed values and attitudes, experience of capability and meaning are more suitable measures of results.

In order to reach the goals of equity in care and equity in health for the whole population, registered nurses must see it their task to work with promotion and prevention. Promotion means working to preserve health. Prevention is about minimising the risks of sickness and ill health. Registered nurses have a responsibility to influence development, partake in society debates and disseminate their knowledge about how people's socioeconomic conditions have impact on health and care.

A person-centred approach means listening to the patient's narrative, becoming conscious of the person's will, motives and resources.

#### Health professionals have knowledge of the consequences of inequity in care, hence the whole team have an ethical responsibility to bring to bear socioeconomic justice.

# PRIORITISED AREAS FOR EQUITY IN CARE AND HEALTH

The portal paragraph of the Health and Medical Services Act (SFS 1982:821) states that care shall be given according to needs and on equitable terms. This means both that persons with the same needs of care shall be offered equitable care, and that persons with greater needs of care shall be prioritised before those with lesser needs. This, in turn, means that if the government's aim – to equalise discrepancies in healthcare within a generation – is to be reached, all who work in healthcare and public medical service must be involved. The public has great confidence in health professionals who thus have unique opportunities through their work to inspire individuals and groups to healthy habits in life. But that is not enough, health professionals must also help abolish inequalities of health by, whenever they see the consequences of the social gradient, calling attention to it and acting.

Apart from the fact that the public has great confidence in them, health professionals have unique access to the majority of people in a population due to the role of care at vital incidences in life, for example pregnancy and birth (midwives, physicians, registered nurses at mother and child health care centres, etc.), during school (physicians and registered nurses, dentists, social workers, psychologists, speech therapists etc.) and during periods of illness (primary healthcare, healthcare centres, hospital care). This gives health professionals the opportunity to have a holistic perspective and to address the social determinants to reach the goal of equity in health.

Most of the factors that influence people's health are not found directly within the area of healthcare and public medical service but within other sectors of society, for example education and access to work and social contacts. Despite this, it is often health professionals who see the consequences and must assist people suffering from different kinds of ill health. Hence, they have experience of the consequences of inequity in health and therefore the whole team has an ethical responsibility to influence change in the direction of social and economic justice, not merely to ensure equal rights to care and treatment.

#### The mutual encounter

Some of the unintended differences in care and treatment of various groups can be explained by the fact that the staff have preconceived ideas, and

generalise about patients' needs and resources stemming from age, sex and level of education. It may also be that the staff have insufficient knowledge and lack the ability to adapt encounters in healthcare to suit the patients' various backgrounds (The Swedish Agency for Health and Care Services Analysis, 2014b).

Encounters between patient and carer that create inequity in care are the opposite of encounters where the situation is shared and understood and mutual openness exists. Patient and carer are valued equal, while a care relationship is also asymmetric because the reason for the encounter is the patient's need of care. It is thus necessary for the carer to reflect on people's mutual dependence on each other and on different aspects of power. This mutual dependency stretches beyond the clinical situation and affects both carer and patient as humans. The patient is in a state of dependency and the carer can influence not only the specific physical care, but also the patient's understanding of his or her self and his or her situation. The patient's health depends on whether the carer has a grasp of practical skills and theoretical knowledge, as well as that the carer has an attitude that facilitates the patient's development. Suffering is unique and individual. Suffering can be described as a feeling of losing control, as a threat or as a violation. All suffering cannot be relieved. Within nursing it is fundamental to relieve suffering whenever possible, and not to cause the patient to suffer. To relieve suffering, the patient's suffering must be acknowledged (Swedish Society of Nursing, 2016).

- Introduce person-centred care with partnership between patient and carer.
- There is a need to develop the function of the contact nurse, and casemanagement models, within several more healthcare sectors than today.

#### Acknowledge the gender perspective

The concept of gender implies that thoughts and descriptions of what is male and female are socially constructed and can be changed. Gender is based on a cultural interpretation of biological differences between men and women (Hirdman, 2003). Inequity between men and women influences health

This mutual dependence goes beyond the clinical situation and affects both the carer and the patient as human beings. **Knowledge** of how gender is constructed in the meeting between patient and registered nurse is necessary in order to treat patients equally.

There has been a positive increase of healthier lifestyle habits during the past ten years, yet still the number of people who are inactive in their spare time is unchanged. Registered nurses' health-promoting interventions when caring for patients needs to be highlighted and documented.

adversely, it is present in all societies in the form of discrimination, unequal division of power and resources, and globally this inequity affects primarily women and girls. Inequity in access to advanced care and treatment is reinforced by the fact that older women on average have a weaker socioeconomic situation than men of the same age. Older women live alone more frequently and often have decidedly lower pensions than men.

By clarifying prejudices, ideas and ingrained ways of thinking, an awareness of gender can be achieved. How gender is created in the encounter between nurses and male/female patients is not sufficiently researched, but the acknowledgement of the gender perspective in nursing care can be contributory to increased equality and equity in care. In order to encounter patients equally, there is a need for knowledge about how gender is constructed in the encounter between patient and nurse.

 Increase knowledge about the significance of gender in education and clinical practice.

#### Good habits in life

To work with health-promoting processes is the health professionals' most important contribution to sustainable development. Health-promotive processes are significant in the support of sustainable societal growth from both social, economic and ecological aspects. In care, this is achieved by the patient participating in his or her own health plan and by receiving support to mobilise his or her own inner and outer resources. Pivotal to person-centred care is the encounter between the person and the care team.

Although the development of healthier lifestyles has been positive over the past ten years, the number of persons who are inactive in their leisure time is unchanged over the same period. Almost a million Swedes are inactive at work and leisure time.

Almost two million adults eat less fruit and vegetables than recommended. Men eat less fruit and greens than women. Low intake of fruit and vegetables is on WHOs list of the ten most significant risk factors for both men's and women's burden of ill health in high-income countries. The proportion of persons with obesity has increased in both sexes, particularly in the age groups 45–84 years old. Obesity is more common among persons with low level of education (The Public Health Agency, 2016).



Dots Obsession 2016 Installation view: YAYOI KUSAMA IN INFINITY at Moderna Museet, Stockholm.

British researchers have conducted a meta-analysis to investigate how giving up smoking impacts mental health. Those who gave up smoking reported decreased mental ill health in the form of anxiety, depression and stress, compared to those who continued to smoke. The effects of giving up smoking were the same in study groups with physical or mental illnesses. The observed effects are similar to treatment of mood disorders and anxiety with anti-depressants. Regardless of whether it is giving up smoking or something else that leads to better mental health, the results reinforce healthcare's continued quest to stop all patients from smoking (Taylor et al, 2014).

Risk use of alcohol is a relatively new concept that means the use of alcohol that can be detrimental to health without fulfilling the diagnostic criteria for abuse. According to SBU (2014), one in ten patients, who have had a short talk about alcohol with a healthcare representative, lower their intake themselves to less dangerous levels.

Socialstyrelsen (2011) has produced guidelines for methods to prevent illness and they lay down a health promotive approach as part of all care and treatment. Questions about habits in life are a given part of the treatment and must be documented and followed up. All who come into contact with healthcare must be offered advice and support if their habits in life are unhealthy. Many patients wish to discuss their habits when they visit care units, but more and better quality discussions are needed. If we are to achieve the goal of equity in health for the whole population, we need to a greater extent support people to take responsibility for their own health and for this to happen, increased collaboration between patients' organisations, schools, social services and voluntary organisations and healthcare's various professionals is needed. The registered nurse has an important role in guiding people to healthy habits and lifestyles, educating and informing about risks to health, and noting and remove unhealthy habits that are a risk to the nation's health. Health-promotive nursing care must be highlighted in clinical care and in the nursing documentation. Evaluation is also required.

- Promotive care, from the whole team, must be integrated with consultative talks about lifestyle habits in all healthcare sectors.
- Work towards a tobacco free Sweden in the year 2025.
- Offer health-promotive consultation in the home for all above the age of 75 years.

#### **Understanding obstacles to physical activity**

A lack of physical activity is one of the main causes of problems of overweight and obesity, particularly among children and adolescents. Although increasing physical activity does not principally lead to weight loss, the activity is significant in improving individual health. Physical activity contributes to improved metabolic and mental health, and this can influence weight over time. Hence, it is important to identify the obstacles to physical activity, both at an individual level and in society. Personal obstacles can be physical or psychological, a person can be too heavy, injured, suffer from sickness and ill health or lack the will and motivation, have mood swings, depression or the side-effects of drugs. Other obstacles can be lack of time, lack of information, other demands and activities or bad weather (McIntosh et al, 2016). The significance of daily activity such as play-time movement and sports cannot be stressed enough in the case of overweight children. Preschools and schools have here a considerable responsibility. It is important to adapt the activities to the child's biological and social development, that children have fun doing the activities and find them pleasurable, and that they stimulate a life-long interest.

In order for registered nurses, and others in the team, to help overweight and obese persons change their lifestyle habits, they must understand their own values and prejudices about overweight and obesity. They must strive to meet a person as a unique individual and treat the problem from a holistic approach to understand the possible reasons for overweight. When dealing with overweight and obesity, it is important to concentrate not only on physical activity but also on other lifestyle habits such as food and alcohol.

Increase the resources for research into obstacles to physical activity.

#### Health for children and adolescents

Mental ill health is one of the most significant problems among children and adolescents today and is usually defined as symptoms that lead to the child suffering, that are lasting and that hinder the child from developing. It can concern children who are prone to outbursts, are obstinate and aggressive or a child that is restless or nervous. It can also concern teenagers who have lost the will to live or young adults who suffer from acute panic disorder. If the problems grow worse, a child's/adolescent's development would be impeded and the risk of serious anxiety or depression increases. Depression and anxiety are more common among girls than among boys. Mental ill

In order for registered nurses, and others in the team, to support persons who are overweight or obese to change their lifestyle habits, they must understand their own values and prejudices against overweight and obese persons.



PUMPKIN 2014 Installation view: YAYOI KUSAMA IN INFINITY at Moderna Museet, Stockholm.

Mental ill health is the most significant problem among children and adolescents today. Underprivileged children run a higher risk of being bullied at school which effects their results, and they do not have equal opportunities for meaningful activities in their leisure time. Their parents' anxiety due to lack of money also influences the children.

health is more common among children who live under psychosocial circumstances that are worse than those of children who have better circumstances (The Public Health Agency, 2016; SBU, 2010; WHO, 2016).

The connection between low socioeconomic status and mental ill health observed in adults is less obvious among children and young people. But although there is not much evidence to show how low socioeconomic status affects children later on in life, it is accepted that socioeconomic status is a significant factor for physical, mental and social development and unequal health-related quality of life among adolescents (Torsheim et al 2004; 2006; Currie et al 2008; 2012). Children and adolescents from low socioeconomic backgrounds are more likely to have lower health-related quality of life than are children and adolescents from groups with higher socioeconomic status (Reiss, 2013; Hutton et al, 2014).

It is therefore of great importance to promote children's and young people's health at an early age. However, research into health promoting activities and programmes used in Sweden today lack sufficient scientific support (SBU, 2010). Preventive long-term activities, organised early on, are significant, from the perspective of society and the individual, in stopping the deterioration of mental ill health.

There is no official definition of poverty in Sweden. According to the Swedish Red Cross, children are poor children if they live in a family where income is not sufficient to sustain necessary costs, or in a family that receives benefits. These conditions influence the children's lives. They run higher risks of being bullied at school which effects their results and they do not have equal opportunities for meaningful activities in their spare time. Their parents' anxiety due to lack of money also influences the children.

The aim of child allowance is to redistribute between persons without and with children regardless of income. Parents are given the means to live at a similar standard as those who choose to live without children. Child allowance is given to all and thus strengthens the will to assist a generous and general family policy.

The physical environment, for example at schools, is also significant to children's and adolescent's experience of health. One example is that there are pupils who absolutely do not want to use the school toilets. Because of this, they avoid drinking anything during school time, believing that this helps not going to the toilet. Another strategy is to keep on the move all the time or bang your feet on the floor to deflect the urge to use the toilet. School work suffers due to lack of concentration, stomach pains and constipation (Norling et al, 2016). We already know that bladder problems in childhood can cause problems as grown up such as an over-active bladder, urinary infection and incomplete opening of the bowels (Kistner, 2009) and constipation can be linked with lower urinary symptoms in children (Averbeck & Madersbacher, 2011). Hence, an improved school toilet environment would be a worthy investment in the health of pupils.

- Increase the child allowance
- Introduce daily physical activity, movement and play at primary and secondary schools
- Prioritise clean school toilets



Persons suffering from persistent mental illness are an identified risk group regarding reduced health, and are thus in need of somatic care more than many other groups.

Even if carers know about the risk factors concerning suicide, they have insufficient knowledge about which methods of prevention are viable.

#### Somatic care for persons with persistent mental illness

Persons suffering from persistent mental ill health have substantial somatic morbidity. They are an identified risk group regarding reduced health due to lifestyle habits, including low physical activity and abuse. Symptoms can be low energy levels and want of motivation.

Although these persons are in greater need of somatic care than other groups, it is well-documented that somatic care for them is lacking (Socialstyrelsen, 2014). A probable explanation is that persons suffering simultaneously from mental and somatic ill health need both specialist psychiatric care and primary care, units that themselves report that they lack competence in the other's field.

However, there are positive examples, exceptional cases, that should be multiplied, i.e. patient facilities for persons suffering from psychotic disorders in the city of Gothenburg. All patients have regular check-ups that focus on weight and blood pressure. This is especially important if they are prescribed anti-psychotic drugs that usually have side-effects such as weight increase and stiffness. A person suffering from psychosis meets a case manager/registered nurse and they write a health plan together, including a daily agenda for exercise and diet, and book a date for a check-up. The aim is to prevent weight increase, keep control of risk factors and preserve the healthy side of those suffering from psychotic disorders (Ali, L., 2016 verbal information).

 Increase competence and accessibility of somatic care for persons with severe mental illnesses.

### Healthcare and knowledge about suicide prevention

The number of suicides has decreased greatly, mainly during the 1990s, but since the year 2000, it is about 1.500 per year. The reasons for every suicide vary, but it is common that mental ill health, in the form of depression, lies behind. Depression is thus a risk factor of suicide. Improved treatment of depression and possibly increased openness about mental ill health is perhaps the reason for the decrease during the 1990s. Today, suicides are decreasing in general, except for the age group 15–24 years where it is increasing every year, particularly for boys and young men.

Although we know about the risk factors for suicide, there is not enough knowledge about which preventive methods that are effective. The healthcare of persons at risk of suicide need improvement, especially since eight out



of ten who take their own lives, have been in contact with healthcare units during the last three months, not only with psychiatric care but just as often with primary care, hospitals and other specialists.

 Improve the care, health professionals' competence and, the accessibility to care for persons at risk for suicide.

## Nursing care for the elderly

There are many examples of age discrimination in the healthcare sector. Socialstyrelsen has previously pointed to shortcomings both of competence and routines in the treatment of elderly at Swedish emergency units. Shortstaffing, inadequate competence of care of older people, and overcrowding

There are many examples of age discrimination in the healthcare sector.

Reasons for the lack of collaboration could be that the structures and organisation of the care sector do not support this aim, routines and tasks take over, and planned collaboration and IT systems do not give enough support.

cause long queues at emergency units and affect frail elderly considerably. Older people should be able to live a dignified life in comfort, and the social services' care must be guided by this. Despite this, there are many elderly who are denied places at nursing homes. They are told that there is no need or that their needs can be met in other ways.

Older people in nursing homes often suffer from the co-existence of two or more long-term conditions, a reduced ability to make decisions and need complex care. Although there is much evidence that shows that qualified nursing competence leads to better care, the proportion of registered nurses at nursing homes is low, and only two percent have specialist education. Rehabilitation and teamwork are limited by the low number of other authorised healthcare professionals. Secondary school carers, or untrained staff, are obliged to take much responsibility as they often work without access to a registered nurse at the nursing home. This means it is also necessary for the registered nurse to delegate the administration of drugs.

Before older people are discharged from hospital care they must be provided with a plan of collaboration between various other care units. Planned collaboration is, because of short length of stay at hospitals, more important than ever before and crucial to how healthcare works after discharge. Although this obligation has existed for a long time, planned collaboration does not work in a satisfactory manner, and older people find it fragmentary and without continuity. Reasons for this lack of collaboration could be that the structures and organisation of healthcare do not support this aim, routines and tasks take over, and IT-systems do not provide support.

The solution could be mobile teams that are dimensioned for continuous care of these patients as described in the case-management model. The first Swedish project with a close-at-hand registered nurse for the care of older people started in 2006 in the city of Lund. It entailed home visits by the registered nurse, at least once a month for planning, follow ups, control and coordination of care activities. The patient received general and specific information about health-related issues and the visit focused on continuity and safety. Visits to primary care physicians by the elderly who took part in the project, were less frequent up to six months after the project ended. The health-economic evaluation showed that they needed less help from informal carers (Sandberg et al, 2015b).

- Reinforce nursing competence at nursing homes with more specialist educated registered nurses.
- Improve continuity and the coordinated healthcare plan for the elderly.



## Support to next of kin

Most next of kin are positive to taking care of a relative at home, but they think that the main responsibility should be with public health authorities. The quality of life of next of kin and their self-assessed state of health is growing worse due to considerable care loads, and only one in four close carers is aware that local authorities are obliged to offer support (Socialstyrelsen, 2012).

The next of kin of persons living at home with dementia feel less burdened and depressed when they receive structured training. SBU (2015) points to this in a systematic survey of international studies of various kinds of education programmes for next of kin. One of these studies was the Swedish MIND-study (Malmö Intervention study for Significant Others of Persons with Dementia) (Andrén et al, 2008a; 2008b, Dahlrup et al, 2011). The MIND-study included both an educational programme combined with support groups

Newly arrived refugees show a higher degree of ill health, or risk of ill health, than persons born in Sweden. The quality of life and self-estimated health of next of kin deteriorates due to comprehensive care and only one in four is aware that local councils are obliged to offer support.

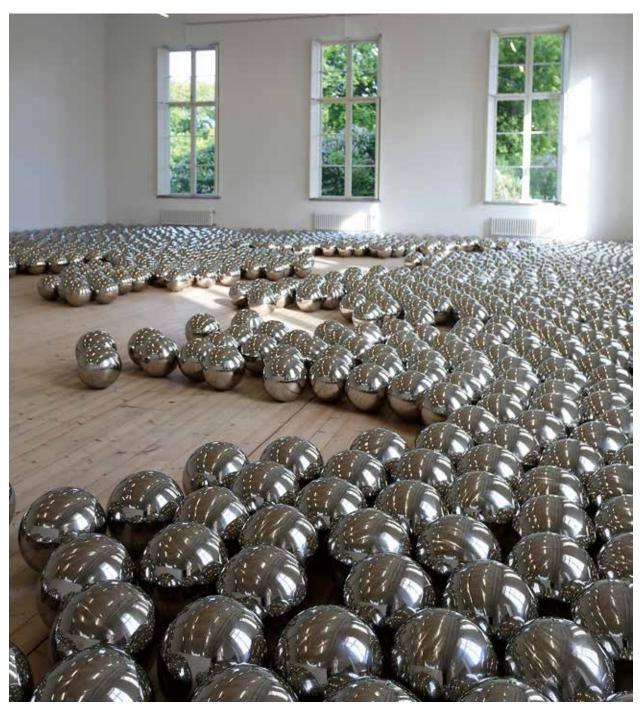
**Newly arrived** refugees need to take part in, and share, the social capital of society as soon as possible to avoid marginalisation and declining health. for next of kin. The leader of the programme was a registered nurse with knowledge of dementia diseases and current legislation, and on top of that was a proficient counsellor with experience of support to next of kin. An economic evaluation of the MIND-study shows that the quality of life of next of kin improved at little cost to the municipality, and that the group of next of kin who were adult children, cared for the person with dementia at home longer than a control group (Dahlrup et al, 2014). Each activity cost the municipality about 100 EUR per participant, a relatively small sum and a feasible way of using the funds allotted to care of older people (SBU, 2015).

- Offer next of kin, children and young people too, support and special education to ease their load.
- Offer next of kin, with relatives suffering from dementia living at home, structured education.

## Health for refugees and asylum seekers

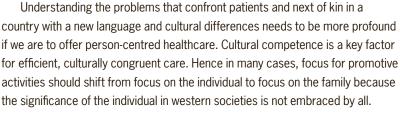
Health is crucial to newly arrived refugees' establishment process. Newly arrived refugees show a higher degree of ill health, or risk of ill health, than persons born in Sweden. What was previously taken for granted, social contacts, networks or living space, can be difficult to achieve in the new country, and this can result in long-term consequences for health. Problems with overweight and obesity are significant in certain groups, but the main problem in all groups is mental ill health. Health has an impact on people's social relationships and can be linked to their social capital, i.e. their trust in other people and in the institutions of society. Trust is created through individuals taking an active part in various social contexts, thereby developing common goals and values. Newly arrived refugees need to share society's social capital as soon as possible to avoid being marginalised and suffering ill health (MILSA, 2015).

Persons fleeing and asylum seekers have different social, political and economic backgrounds and they come with many different experiences, behaviours and values with relation to health and sickness. Many have had dangerous and frightening experiences of war and political persecution in their countries and these are the reasons for their, in many cases, disastrous flight. Other factors such as country of birth, level of education, the ability to communicate in English or another language, and social capital have an impact on a person's health and potential risks of ill health and disease.



Narcissus Garden 2016 Installation view: YAYOI KUSAMA IN INFINITY at Moderna Museet, Stockholm.

Cultural competence is a key factor for efficient, culturally congruent care.

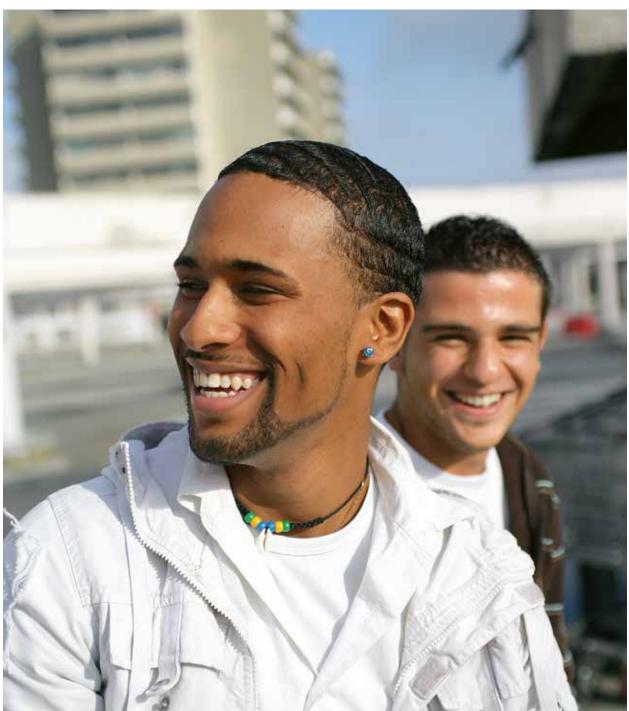


For many reasons the lifestyles and habits of newly arrived persons are often unhealthy. It can depend on their social situation, for example uncertain accommodation where keeping to daily food routines is difficult, uncertainty about food products in a new country or a vulnerable economic situation.

All newly arrived persons are offered a talk about their health. This conversation is part of the health examination. The conversation aims at acquiring information about the person's background, eventual symptoms and history of vaccinations, and to give information about Swedish healthcare and public medical service. The health examination gives details about the newly arrived person's previous and current physical and mental health, psychosocial situation and experience of traumatic episodes. The dialogue contains questions about vaccinations, exposure to infections and other details that can be necessary from the aspect of infectious disease prevention. The conversation can be used to motivate a person to take part in health-promotive group activities. One example from Stockholm is the Trans Cultural Centre where health communicators work with dialogue meetings to create conditions that boost mutual learning. Other areas that can be highlighted in health-promotive group activities are diets, self-care, stress and sleep, physical activity and the consequences of genital mutilation. By offering these activities the health communicators act as a bridge between the partaking persons and the healthcare and public medical service sector.

Because health-promoting activities are not just about lifestyles and habits, registered nurses can contribute also to increased social capital for newly arrived persons, asylum seekers and refugees.

- Give undocumented persons the right to equity in care.
- The humanitarian call for all people's right to care, and to culture congruent care, is a knowledge area that must be included in all healthcare education, i.e. the whole team must have this knowledge.



Colourbox

**A complete** list of references is available at www.swenurse. se/jamlik-vard-och-halsa.

## A POLICY FOR EQUITY IN CARE AND HEALTH – TEN REQUIREMENTS

This is a summary of the Swedish Society of Nursing's requirements to achieve the goal of equity in care and health:

- Health-promotive work needs a clear and long-term national commitment executed by county councils, regions and municipalities.
- Leadership tasks at all levels from municipality, county council/regions to government shall include active monitoring with the goal to contribute to equity in care and health.
- Knowledge about conditions in society that affect health, and knowledge about health-promotive work and the prevention of disease, shall be included in all education that lead to regulated professions.
- To counteract inequity in care and health, and also to highlight the significance of health-promotive activities, there is a need for successful activities and projects to be disseminated across the whole country.
- Economic and human resources are needed for health-promotive nursing care, the results of which include care and health effects in the form of patient satisfaction with certain activities, the consequences of the intervention and changes in perceived health.
- Introduce person-centred nursing with partnership for the patient where
  there is mutual respect for the other's knowledge in the encounter, i.e. the
  patient's and next of kin knowledge of what it is like to live with the disease,
  and the professional's knowledge about care, treatment and rehabilitation.
- Increase knowledge about activities that promote equity in health. Research must be reinforced and merit the whole of the health professions.
- There is a need to allocate economic resources to research concerning interventions and registered nurses' competence that can prevent ill health and promote healthy lifestyles.

- Sweden needs a national NCD strategy that focuses on public collaboration with the goal to decrease non-communicable diseases in Sweden, in harmonisation with global work, WHO plans of action and recommendations.
- Knowledge about the introduction and influences of digital services on nursing care must be researched and how information technology within care can best contribute to learning and development of competence for patients', next of kin and staff.





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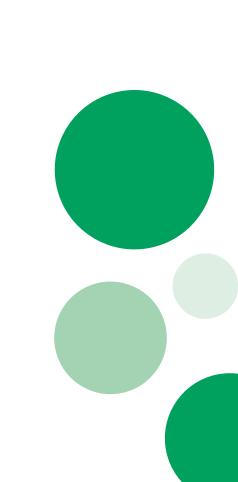
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