The value and benefits of home modification services for older people. Views of the user, the caregiver, and the next of kin.

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What is the value of a modified home? When the home becomes the place where an increasing number of very sick and frail persons will be taken care of, the need for adjusted homes will grow. This paper describes the results of an empirical study investigating the value and benefits of home modification services (See Appendix).

A home environment must suit the specific person with functional impairments, and at the same time provide a good work environment to prevent health problems in relatives and nurses working there. If a person is lucky enough to become old, he or she will probably get functional limitations of some kind. These limitations might prevent the person from, for example transporting him- or herself without assistive devices, or to see properly. Since many houses are not built with respect to this, obstacles must be taken care of afterwards with the help of assistive devices and home modifications (HM). Otherwise, the physical environment will create a situation where the persons living in the home, become more handicapped than necessary (see ICF, 2001). The discussion about the need for building accessible homes is not new, it has been going on since the 1950s (Paulsson, 2002).

In Sweden “the remain-at-home principle” has been discussed since the 1950s (Wånell, 2000), and applied to the elderly care from the 1980s (Paulsson, 2002). This principle is based on the idea that people can have more quality of life, if remaining in their private homes. Thus, people in need of care should be able to remain at home as long as possible and not be forced to move. There are also empirical studies supporting the idea that elderly wish to remain at home (Wånell, 2000). A circumstance that increases the need for home modifications is that the older part of the population in Sweden, often lives in the oldest and least accessible houses (Hurtig & Paulsson, 1986). Approximately 60,000 modifications are made possible by a public grant each year, and the number is increasing (Fänge, 2004). This increase is probably related to the increase of elderly in the society.

If viewed from a historical perspective, changes within the elderly care policy are noticeable from the time when residential care was associated with housing for the penniless, to the very different situation today. A great amount of effort has been made in order to try to get rid of
the old stigma associated with residential care (Lo-Johansson, 1952; Wånell, 2000). After the
1940s the ambition has been to attract elderly from all socio-economical backgrounds to move
to residential care units. Nowadays, it is rather a privilege to be allowed to go there. In the
light of the demographic situation with a fast increase of the elderly in society, decision
makers have started to question the value of residential care. An important driving force
behind this change is financial, since the costs for residential care is much higher than for
home care. In Sweden, in the year 2003 the costs for the residential care stood for 70 % of the
total costs of the elderly care, while only 7 % of the population 65 years and older benefit
from it (Socialstyrelsen, 2004b).

Previous research within the area

This research topic has implications for many disciplines such as: architecture, health
sciences, psychology, and sociology. Despite this very few investigations have been carried
out. Preliminary results from a larger investigation in Stockholm, suggest that modifying the
home can enhance functional independence for older people, and reduce the burden of care
for their caregivers (Lilja, 2003). A study that investigated the benefits of both assistive
devices and home modifications (HM) was based on the answers from approximately 200
elderly one year after suffering from stroke. The conclusions drawn from this study was that
these services were of a great value for the former stroke patients. They experienced more
independence and a higher degree of security, and could live a more active life than they
would have been able to if not having received this help. Moreover, if the costs for assistive
devices and HM were compared with the average cost for the health care and rehabilitation of
a stroke patient during one year, it represented only 2 % of the total expense (Gosman-
Hedström, 2001).

In a smaller study including ten next of kin to stroke patients, the results showed that all
participants thought of the HM in positive terms. The HM gave them a feeling of freedom. It
also facilitated the use of assistive devices, especially the use of wheelchair and walking aids.
The next of kin considered the HM as a necessary change of the home, and did not wish to
move. Many of them felt deeply rooted to their home environment. Some of them had lived
there for 40 years (Bergman & Bäckström, 2001).
It is interesting to know whether the homes contain physical obstacles in general. A study with 63 persons with Parkinson’s disease showed that 71 % of them judged their physical home environment as accessible. This means that nearly 30 % experienced physical obstacles within their home. The problems that the respondents reported consisted of height differences between rooms, lack of modifications of kitchen and bathroom, and too narrow spaces (Enesund & Norrman, 2002).

One study investigated if occupational therapist experienced ethical dilemmas related to prescriptions of assistive devices and home modifications. It was found that ethical conflicts were more common in the cases of assistive devices. However, the respondents also described conflicts related to the caregivers’ wishes to rearrange furniture in the homes (Grahn-Ähl & Thyborn, 2001).

The benefits of home modifications are seldom evaluated afterwards. One recently written dissertation deals with the issue of creating strategies and methods for evaluations of HM. The researcher has created a self-administrative-instrument on the usability of the home. The results of her studies showed that both the accessibility and the usability of the homes increased after a HM, as measured with the instruments. (Fänge, 2004)

The conclusions that can be made from previous results are somewhat restricted due to the fact that some studies are very small, or have investigated both assistive devices and home modifications, which makes harder to draw clear conclusions about HM. Many studies are also targeting specific diagnose groups which raises the question whether the results can be generalised to other groups of HM recipients as well.

Aim and research questions

To examine and understand the value and benefits of HM, the present study will describe how different stakeholders perceive the value and benefits of home modification. This study is the first part of a two-phase design that integrates qualitative and quantitative methodologies. Methods are combined to provide stakeholder insights and perspectives in order to gain a better understanding of the outcome of HM.
This paper will describe the value and benefits of HM from three different perspectives:

1. The users’ perspective, i.e., persons with functional limitations who have received a HM during the last 6 months.
2. The next of kin’s perspective, i.e., relatives who are involved in the care
3. Caregivers’ perspective: occupational therapists who perform assessments and write certificates, nurses and personal assistants working in private homes.

Method

Semi-structured interviews and focus group discussions with different target groups (see above) were used for the data collection. The study includes users of different ages, diagnoses, and home modifications. The subgroup with older respondents are described separately.

Recruitment

The users. The users were recruited from list of names distributed from the office of HM services in Gothenburg City. We asked for names of users who were both satisfied and dissatisfied with the HM. In order to include persons of different socio-economic background and housing, we asked for users living in the four cardinal points of Gothenburg city,

The inclusion criterion was that they should have received a larger home modification within 6 months from the start of the investigation. By a larger HM meant that it had cost approximately 30,000 SEK or more, or include more than one modification. This criterion included users who received shower cabins, ramps, automatic door openers, garages for the wheelchair etc. We excluded users who only received smaller HM such as removing of thresholds.

Letters were sent to 33 users with information about the study. Twenty-eight of them were contacted by telephone. Seventeen of them accepted participation and were interviewed in their homes. Five users were not asked to give an interview. The drop-out analysis showed that eleven users could not or did not want to participate (33 %). Five of them were older than
65 years. The reason for the elderly to reject participation was that they were too tired, or had hearing problems. In one case the user had died very suddenly.

*The next of kin.* The recruitment of the next of kin was made with the use of different sources. The name lists of users (see above) were also used to come in contact with relatives. Moreover, we tried to find the target group via voluntary organisations for retired persons (SPF and PRO), and handicap organisations (HSO and RBU). We also contacted civil servants with the task of supporting persons who take care of their relatives (anhörigkonsulenter).

*The caregivers.* The *occupational therapists* play a specific role when it comes to HM. They assess and judge a person’s functional status in the home environment and writes a certificate based on this. Occupational therapists is the professional group that, besides the civil servants who administrate the benefits for home modifications, has the greatest experience in these matters. Hence, it is important to capture their perspective of the value and benefits of HM. The occupational therapists were recruited based on lists at the office of HM services of therapists who had quite recently written certificates. They represented the different organisations within the health care sector.

*The nurses and personal assistants* were recruited with the help of senior managers in the elderly care and functional disability sectors within Gothenburg. The recruitment of the staff represented the four cardinal points of Gothenburg. Inclusion criteria were that the staff had experience of working in a modified home, and had at least one year of working experience.
Procedure

As shown in Table 1, seventeen personal in-depth interviews were made with the users. Five of the users were older than 65 years (2 men and 3 women). All interviews were carried out in the respondents’ homes and lasted between 1-2 hours.

Seven interviews were made with relatives who took great part in the daily care of their husband, wife, or child. Five of them were older than 65 years (2 men and 3 women). Two interviews were made at home of the respondent and lasted approximately one hour, while the other three were carried out as telephone interviews and lasted between 30 minutes and one hour.

One group discussion was organised with occupational therapists. Nine occupational therapists with experiences from HM participated in a group discussion of 2,5 hours.

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<th>Users</th>
<th>Next of Kin</th>
<th>Occupational therapists</th>
<th>Nurses and Personal assistants</th>
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<td>9</td>
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<td>In Total</td>
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Five personal interviews were made with personal assistants and nurses working in private homes. Each interview lasted one hour, and was documented by note takings that were transcribed immediately after the interview. In addition to the interviews, four groups with personal assistants and nurses (in total 14 participants) met for discussions of different types and length. Two groups met for discussions of 2 hours outside their office, with the specific aim of discussing the physical environment when working in private homes, and the benefits of HM. Two other groups were participating in a shorter discussion during one of their regular meetings at the work place.

Instruments

Different interview guides and discussion guides (for the group interviews) were used for the different target groups in the study. The guides included different themes to facilitate for the
participants in telling us about their experiences of the HM. In addition, we used questionnaires to capture background information about the participants.

Documentation and analysis

All user interviews were recorded with audio tape and transcribed word-by-word. The next of kin interviews and interviews with the professional caregivers (both individual and group) were documented by note takings and were transcribed immediately after the interviews. Audio recording was sometimes used during group discussions, but served only as a memory support.

The content of the interviews (both individual and group), were analysed in line with grounded theory procedures (Strauss & Corbin, 1997). Grounded theory is an inductive method with roots in the symbolic interactionism (Mead, 1969). The analyses were made to identify meaning and intentions in the stories of the informants. The aim was to, out of empirical data, generate constructs and concepts, and to describe the relationship between the them with respect to the overall research question. The ambition was to give a conclusive description of the results from each target group.

Research ethics

The participants of the study were informed of the ethical grounds of the research, that:

- It was voluntary to participate, meaning that they could withdraw from the study at any time
- The information was considered confidential and could not be used for any other purposes than research
- Study participants were allowed to give comments on the results before publishing
- Results of the study would not contain details that reveal any individual persons
- Participants were offered a copy of the full report
Results

The users

The interviews with the users showed that home modifications consisted of two different aspects of change: both a physical/material change, and a psychological/social change. Another way to put it is that HM is a process with a physical/material result that is tangible, but with an effect that is psychological/social and intangible. For example, the removal of a bathtub and installation of a shower cabin is a physical change. The anticipated effect of this is that the user will be able to manage his or her personal hygiene by him-/herself, which creates a feeling of satisfaction and independence that is of psychological/social nature.

An interesting question is whether the process of applying for a HM affects the outcome of it. If this process involves a lot of insecurity and time of waiting, the psychological/social outcome might be more negative than if it was the opposite. Many users witnessed about the insecurity they felt concerning the time. However, the application process will not be dealt with further here.

The difference between the value of and benefits of HM, can be concluded as follows. The benefits deal more with the practical consequences of the modification, while the value and meaning to a higher degree concern the psychological/social change (see figure 1). However, the values and benefits are rather intertwined than separate from each other.

The value and benefits of HM can be put in relation to the presence of available alternatives to obtain the same effect. Furthermore, the value and benefits can be considered in the light of the context around the user. In what life situation is the HM introduced? What difficulties due to his or her frailty or functional limitations does the user experience? If the HM was not applied, which activities would the users be unable to perform? Figure 1 below tries to visualise the two points of references related to the evaluation of the benefits and value of home modifications.
The physical/material changes appear when a home is modified. They enable the user to satisfy basic needs such as the possibility to go outdoors (e.g., by means of ramps), manage personal hygiene without external help (e.g., with a shower cabin). These are examples of concrete benefits of the modifications. The ability to manage these things is of a psychological and social value for the user. As one 67-years-old woman who received a shower cabin expressed it; “I can tell you that it means a lot. To be able to feel like a human being and manage by myself.” Hence, the benefits are not separate from values of a modification. Benefits and values are interrelated, as different aspects of the same situation.

The physical/material change is always one of many possible solutions to a problem in the home environment. Thus, the benefits must be viewed in the light of alternative solutions. For example, certain assistive devices might replace the installation of a HM. Another alternative solution is to get help from a relative or a professional nurse to manage the activities that could not be done alone. “(What did you do when you could not take a shower at home?) Actually I went with my son to his clubhouse, because of the convenient showers they have there. I felt secure that he could lift me up if needed.” (69-years-old man who had received a shower at home)
If stairs prevent a user to go outdoors, an alternative solution could be to move to another apartment or house. However, none of the users that we interviewed saw moving as an alternative to the HM.

The value and meaning of a certain HM can be viewed in relation to the context around each user. The user has often been forced to accept negative changes before the application of HM. Users describe how they have been forced to give up things they enjoyed, for example, driving their car, going out with the boat, visiting theatres and cinemas, or to meet friends at the swimming hall. Some of them had lost contact with their friends all together. Many of them also described their struggle to get the proper diagnosis, and to get help from the society. As one woman around 70 years of age, who received a new shower, ramps in the entrance, and an automatic door opener put it; “We have avoided some things. We have not been to the theatre. (-But has it been important for your husband?) Oh, my God. It is hard for him. [almost whispers] He could not bear it any more. He is tired enough.”

The next of kin

Older relatives often expressed that it is a matter of course to take care of their next of kin. They do not see any alternative. They express scepticism concerning the help that can be provided from society, and also see it as a matter of honour to cope by themselves. Most of them do not even want to leave their next of kin for a temporary visit at residential care to get some ease from the burden. They identify with the needs and worry about their relative. As caretakers, some of the next-of-kin get a smaller benefit, but claim that they are being used by society since this solution is much cheaper than professional care.

The predominant picture of the relatives’ situation is that they feel tied up due to the fact that their husband, wife, or child, has become very dependent on them. It is psychologically demanding. “(-Do you feel tied up?) Yes, very tied up. I can make smaller excursions to the Botanic garden. Can not be away for too long, I worry. Things can of course happen when a person sits in a wheelchair.” (79-years-old man who takes care of his wife)

In situations when a user is prevented from going out, the next of kin seldom goes out themselves. In such cases, the home modification can be experienced as a relief. A HM in the presence of e.g., a stair lift or ramps can bring new life to these people.
The burden of a relative is sometimes very tiring. One woman, who took care of her husband with Alzheimer’s disease, described her experience of physical pain and extreme tiredness. Her husband acted as a small child in many situations and she felt very sad and lonely because she did not recognise her husband anymore. In the light of this description, a new shower is of a very little support to this couple.

All relatives above 65 years of age that we interviewed had health problems. For example, one woman around 80 years of age who always used a walking aid outdoors, still took care of her 60-years-old son. He weighed around 100 kg, and needed very much help to e.g., transport himself to and from his wheelchair.

It can mean a lot for the caretaker to get rid of even smaller efforts, like having to lift up the user’s legs, since such activities are repeated several times during the day. The following citation is taken from an interview with a woman who takes care of her 82-years-old husband who suffered from a stroke: “It [the new shower solution] is of physical help for me. I have constant pain in my neck and shoulders. It is very heavy to help him. Sometimes when he has been sitting for a long time, he cannot get up from the chair. It is heavy to help him up. So it becomes a little less hard.”

To summarise, the benefits of home modifications for the next of kin were:

- To diminish pain that was caused by lifting the spouse in the shower - A narrow shower cabin with a high edge was taken down.
- To be able to go out, and not being imprisoned - A wheelchair and stair lift in combination, made it possible.
- To diminish worry, not having to be available all the time and take care of the needs of the relative - A shower, ramps in the entrance and an automatic door opener was installed.

The caregivers

Occupational therapists. The occupational therapists believed that the information given about HM is insufficient. Very few of the patients that they met knew about the possibility of getting the benefit, which meant that the therapists had to play the role of being informants as
well. The therapists also acted as the “spider in the net” communicating with the different actors involved in a HM case: for instance the users, the real estate owners, the civil servants at the office of HM benefits, the entrepreneurs.

The overall benefits of HM, both for young and old, were described by the occupational therapists as:

- To secure the situation at home – which reduces the risk of falling and as an effect of this the need of health care services
- To facilitate the daily life of the family – both the user and the next of kin, which diminishes the risk that families will split (by separation)
- To enhance the quality of life – persons are more satisfied if being more independent
- To diminish pain of patients – they do not have to stretch the limits of their bodies
- To give staff who are working at home a better work environment. “Sometimes it is as much about their needs.”

*Nurses and personal assistants.* For the nurses and personal assistants, the HM within the homes of the users, influences their own work environment. Within Gothenburg city, there is a big variety of houses and apartments. Parts of the town are more country like, where older persons live in old-fashion houses, sometimes even without an indoor WC. Many elderly also live in the typical houses of Gothenburg called landshövdingehus (county governor houses), three floors high and without elevators. The best work situation is found in some parts of the town where specific handicap apartments have been built, making the daily work much easier for the staff.

If a home cannot be adapted for the user, the nurse/personal assistant (PA) must adapt him- or herself to the environment. The staff describes themselves as sensitive and flexible, not only according to the needs of the users, but also in relation to the different physical demands of their work. But there is a negative side of this flexibility. Almost all the interviewed nurses and PAs had problems with their backs, necks, or shoulders. Furthermore, none of them thought it was possible when working in people’s private homes, to close a working place due to bad work environment, which is otherwise possible according to Swedish law.
The strain is both physical and psychological. As one PA who worked with users living in adjusted handicap apartments described the situation;

“(What does the HM mean to you as an employee?) In an ordinary bathroom you don’t get enough room and it is very demanding both physically and psychologically. (What do you mean with physically?) For the back and shoulders. (What do you think of when you say psychologically?) If it is cramped and you cannot reach, you become irritated. It is strenuous. But before, I’ve worked with a man who lived in an ordinary apartment that wasn’t modified. It was much worse.”

To summarise, problems within the homes described by the nurses and PAs, concerned:

- Homes that are impossible to modify due to how they are designed. “It would be much better if the users were forced to move.”
- Narrow doorways that do not allow a person in a wheelchair to pass, or two persons to pass side-by-side.
- Narrow toilets that do not allow two persons to help the user to move to and from the toilet seat.
- Bathtubs that cannot be used by the user, due to inability to lift their legs. “We have one user, I don’t know how long ago it was since she took a shower”
- Narrow showers with a washbasin in the way for the staff and shower fastenings too high up.
- Narrow kitchens with no space between the kitchen sink and a user who sits in a wheelchair.
- Thresholds in homes where the user sits in a wheelchair. Every lift over a threshold causes strain in the neck and shoulders of the staff.

The workload is sometimes very high. Some users are very heavy and immobile, making them incapable of supporting any movements themselves. The staff is often exposed to skewed lifts and to unhealthy environments, and dislike the fact that there is no room for preventive HM. In some cases, they work with users who have a degenerative diagnosis indicating a future increase of impairments. It is also very common that nurses and personal assistants work with palliative care with patients living at home. They become very dependent and in the end need a lot of equipment and adjustments. If modifications could be planned in advance, some of the workload might be reduced.
Although it is very rare, it happens that the staff takes the initiative of a home modification. It can be due to a work situation that is very strenuous for the nurse or PA, and in some cases by the need of the user. However, according to the law of home modification services, benefits can never be received due to the needs of the staff (Boverket, 2000). Moreover, nurses and PAs wish to be involved when a HM is planned. When the home is already modified it is much harder to change anything. Today, their viewpoints are seldom taken into account.

The nurses and PAs believe that the most important benefit of HM is that users can remain at home. The staff experience that because of security reasons, the older users they meet, wish to live in their private homes.

Conclusions

The image of the results from this study is clear-cut showing that the modifications of the homes of the elderly are experienced as being both beneficial and of a high value. This is in line with previous research (See e.g., Lilja, 2003; Gosman-Hedström, 2001). The unique value of the present study is the inclusion of three different perspectives; the user’s, the next of kin’s, and the caregivers’. The fact that we have asked nurses and personal assistants about their experiences of HM seems unusual compared to previous studies.

The results show that it would lead to many consequences if the homes were not adapted to the needs of the users. It would restrict the users from activities that other people take for granted, such as going outdoors and managing their personal hygiene. The modifications are also important for the next of kin and the caregivers.

It was found that the home modifications create two types of changes: a physical/material change, and a psychological/social. The benefits and values can be related and described in relation to these changes. Moreover, the benefits and values can be evaluated in relation to alternative solutions to solve the needs of the user. The context around the user, e.g., the total amount of losses experienced due to the functional impairments, is another point of reference to use when evaluating the value and benefits.
The results show that the image of the value and benefits of HM coincides between the three target groups. However, differences were also displayed, reflecting the different roles the groups have. The users describe the benefits of the modifications in terms of being less dependent on others, feeling like a human being, or getting a feeling of normalness back. They perceive the home modifications as necessary to be able to remain living at home.

The next of kin who participated in the study were elderly themselves. We also found out that they all had health problems such as fibromyalgia, difficulties walking, and hurt backs. They described their benefits of the home modification as diminished pain, worry and easing of their burdens. If HM is viewed from this contextual information, the benefits provided from the society seem even more important through reducing the burden on the close relatives.

The occupational therapists described the values and benefits of HM from three different perspectives: the user’s, the family’s, and the societal perspective. For instance, they saw the HM as a mean to reduce the risk of falling and getting fractures, in other words preventing both human pain and costs for health care. HM might also diminish the risk of family split ups, by facilitating the situation for the next of kin.

Nurses and personal assistants described how they identified with the users they worked with. If the home was not adapted according to the needs of the user (e.g., making a person imprisoned), it affected the staff’s feelings as well. The caregivers described difficulties related to thresholds, kitchen, bathrooms, and narrow spaces. They experienced both physical and psychological strain when the home was not suitable to work in. Some of them seemed to put an honour in being flexible according to the home environment even though it was very demanding. If viewed in the context that almost all caregivers had bad backs and shoulders, the home modifications were of a great value for them.

Even though it is not very common, it happens that the staff takes the initiative of applying a home modification. This can be caused by a work situation that is very strenuous for the nurse or PA, and in some cases by the need of the user. However, according to the law, the benefits can never be received due to the needs of the staff (Boverket, 2000, 2003). The rule that the adaptation must be based on the needs of the user is based on the idea that the employer is
responsible for the work environment of their employees. Since the employer does not control private homes, the dilemmas have to be resolved between the staff and the user.

This study has not investigated whether elderly with functional limitations receive as many home modifications as younger persons. Wånell (2000) has found that elderly receive less expensive modifications than younger persons. The important question is if this reflects that elderly have less needs of home modifications, or if it is due to assessments and judgements that are discriminating the older part of the population. To be able to investigate this question, we need to make a quantitative study with a bigger sample.

References


Appendix

Definitions of concepts
The concept “home modification” stands for changes of the home that is in the form of a “fixed or permanent installation”. Some examples of the more common modifications are: removal of thresholds, installation of stove timers, shower cabins, stairway lifts, automatic door openers, automatically adjustable kitchen units, automatic toiletties, wheelchair garages and modified lighting arrangements.

“Home modification benefits/grants” are given to persons with a lasting disability and for this reason are in need of a modification of their home. The home may be privately owned or belong to the municipality and consist of apartments, condominiums or one family house. The benefit is most commonly, but not exclusively, applied to the permanent home of the disabled person. The need for a modification must be established by a professional who assesses the necessity of the modification. Most often this is an occupational therapist or sometimes a physician. The general goal with the home modification benefit is that it should contribute to the recipients independence (§1 BAB). The benefit is granted by the municipality and there are no limitations to how high the sum can be. The benefit is not tested in relation to the recipient’s income level either. The public expenses for the grant increased by 15% between 1998 and 2001 (Socialstyrelsen, 2004a).

The concepts of “value” and “benefit” have different meanings. The concept of “value” in this study corresponds with the moral grounding of the individual or group. The term “fundamental values” is sometimes used to imply unconditional principals such as all humans equal worth, the right to life and so on. Fundamental values are also expressed in the UN’s Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The UN standard rules is an example of values that are formed on an international level. On a national level, values can be found expressed in the form of the Swedish constitution and in the Healthcare and the Social Services Laws. The values that are referred to in this study, however, are on the level of the individual: values that individuals express as their own.

The concept of ”benefit” has its roots in the British philosophy of Utilitarianism (e.g. J. Bentham, J.S. Mill). There are different directions or alignments within utilitarianism itself. Common for all of them is the attempt to reach maximal happiness, escape unhappiness and
achieve ones wishes or ideals. According to Action Utilitarianism the consequences of an action should be judged before it is performed (Tännsjö, 1998).