Risk profiling and screening for colorectal cancer
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Individual responsibility, solidarity and differentiation in health care

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Abstract

Objectives
Access to health care in most western societies is based on equality. Rapidly rising costs have fuelled debates about differentiation in access to health care. We assessed the public’s perceptions and attitudes about differentiation in health care according to lifestyle behaviour.

Methods
A vignette study was undertaken in participants in a colorectal cancer screening pilot program in the Netherlands. Screenees with a negative test result received a questionnaire in which nine hypothetical situations were described: three different health care settings (screening, lung cancer, COPD) combined with three forms of differentiation each: a difference in premium, waiting list ordering or co-payment according to lifestyle. We evaluated the responses using a general hierarchical linear model.

Results
The percentage of participants in agreement with differentiation varied from 20% to 58% (overall mean of 40%). Significantly more participants were in favour of giving a premium discount to those who do not engage in unhealthy behaviour compared to supporters for higher payments for those who do. More differentiation was supported for non smoking versus smoking cessation than for participation versus non-participation in screening. We observed in-group favouritism in smokers, but no significant effects of age or disease. There was no support for waiting list ordering based on lifestyle.

Conclusion
Results of this study show that Dutch citizens eligible for colorectal cancer screening are in favour of some form of financial differentiation in the distribution of health care, but that significant differences exist between type of setting, and the type of behaviour. Our study can be used in the on-going discussion about solidarity and behaviour in health care.
Background

Equity in access to health care is and has been a central element in many health care policies. However, because of increasing costs due to increasing consumption of health care, the need for some form of differentiation (inequity) on the basis of lifestyle has recently become a topic of a wide discussion.

The basic concept behind equity and solidarity is based on mutual obligations between members of a community. In principle solidarity is a ‘two-sided’ system that entails elements of receiving and elements of contributing. Individual members of a society should not just be passive recipients of services but should actively contribute and try to avoid harming the system. Members of society should act responsibly in order to maintain the resources for solidarity.

Unhealthy behavior is held accountable for a substantial part of the increasing health care costs in developed countries. This has fuelled a debate on the boundaries of solidarity, and on individual lifestyle and its consequences for health and health care. Can those who have an unhealthy lifestyle demand solidarity from those who live healthily? The general public seems to be willing to take certain lifestyle habits into consideration when deciding who gets treatment or financial benefits. Willingness to pay the costs associated with health problems is significantly lower if those problems are related to health behaviour.

In the Dutch health care system individuals are obliged by law to have health care insurance. At the moment there is no differentiation in premiums for individuals with healthy or unhealthy behaviour. It is known that having equal access to health care, independent of behaviour, can entail ex ante moral hazard: adopting or maintaining risky life styles because one does not pay for the consequences. This unhealthy or risk related behaviour could be seen as a reason to differentiate in access to health care. Ex ante moral hazard can change the public’s view on solidarity and might change the public’s ideas about individual responsibility in health. In this process, one may consider differentiation in certain groups in the allocation of health care. Those with unhealthy behaviour would pay higher insurance premiums or, in the case of disease, pay more for their treatment. Another option could be that individuals with unhealthy behaviour would have to wait longer for treatment in situations of scarcity.

Such differentiation is not undisputed. While some have argued that there could be a significant role for individual responsibility in the usage of health care resources others defend the opposite, saying that those with unhealthy lifestyles lack a basic condition for responsibility, namely liberty. In these discussions self-interest could also come into play, in the form of in-group favouritism. Research has shown that smoking status of
participants predicts their answers in studies regarding health behaviour.3

Until now, the discussion about differentiation in healthcare has mainly been a
discussion of policy makers and politicians. Not much is known about the views and
ideas of the lay public. The aim of this study was to explore the ‘public’s’ perceptions and
attitudes about differentiation in health care according to lifestyle behaviour. We used a
convenience sample of colorectal cancer screening participants, who we questioned about
their own health behaviour. We acknowledge that this sample is not a random sample
of the Dutch population since these participants already completed screening, though
the characteristics of the population are consistent with those of the Dutch population.
Our study supplies information about the views of a part of the general public (those who
completed colorectal cancer screening) on differentiation in health care.

Methods
Participants
This study was embedded in a population screening program for colorectal cancer (CRC),
which is described below. In this program we sent a questionnaire to all participants who
had tested negative on the Fecal Immunochemical Test (FIT). The questionnaire was not
sent to participants who tested positive, because we did not want to add any burden or
distress to them, since they were offered to undergo a colonoscopy after the positive test
result. The questionnaire could be returned to the researchers anonymously by prepaid
postal mail.

Screening participants were between 50 and 75 years of age. We sent out the invitation
to participate in this questionnaire study to all 4,136 FIT negative screenees, of which
2,946 (71%) returned the questionnaire. Baseline characteristics of the participants are
summarized in Table 2; 56% of the participants were male. Fifteen per cent were current
smokers, a proportion in line with numbers in the Dutch population.7

Screening program
Data were collected in the third round of a colorectal cancer screening pilot program in the
Netherlands, in which 10,050 average risk individuals (50 to 75 years of age) were invited
to participate.14 The pilot program had received permission from the population screening
subcommittee of the Dutch Health Council prior to the start of the program.

Screening invitees were randomly selected from the electronic database of the regional
municipal administration registration. Invitations were sent out between July 2011 and
December 2011 by postal mail. The invitation included an information brochure, a Fecal

140
Immunochemical Test kit and a return envelope. If the test was positive, the screenee was invited for a colonoscopy.

**Questionnaire**

The questionnaire, used in the colorectal cancer pilot program, included statements about differentiation in health care related to health behaviour. Based on a review of the literature, a vignette study was chosen as the method for assessing our research question (appendix 1). The questionnaire was in Dutch; a translation of the questionnaire has been enclosed in the appendix. Three health problems were presented, each consisting of a health care setting and a form of health behaviour. The first setting was about population screening for colorectal cancer and a later diagnosis of colorectal cancer, the second about smoking and lung cancer, and the third smoking cessation and chronic obstructive pulmonary disease (COPD). The corresponding health behaviours were: participation in screening, having stopped smoking, and participation in a smoking cessation program. Three possible forms of differentiation were presented in each setting: a discount in insurance premium for healthy behaviour, a financial penalty (co-payment) in the case of unhealthy behaviour, and a lower priority on the waiting list in the case of unhealthy behaviour. By combining the three forms of health behavior with the three consequences in a full factorial design, nine hypothetical situations were created (appendix 1). For each of these situations, participants were asked whether they agreed or not with health care differentiation. This was a yes/no type of question. The nine situations were presented in a single, fixed order.

**Validation of the questionnaire**

The questionnaire had been validated in a pilot study, in which 20 patients of the outpatient department of gastroenterology of our hospital had been asked to complete the questionnaire during a ‘think aloud’ procedure. Minor modifications in wording and presentation were made after the validation exercise.

**Analysis**

We expected the proportion of participants agreeing with differentiation based on forms of health behaviour to differ according to setting (screening, smoking, smoking cessation) and according to the type of differentiation (premium discount, co-payment, waiting list positioning). We also expected the proportion of participants agreeing with differentiation to be associated with their personal characteristics. In particular, we analysed whether the willingness to differentiate was associated with age, sex, level
of education, country of birth, marital status, children, smoking status, disease status, illiteracy, and personal perception of health status.

We analysed the data with a multivariable hierarchical general linear model. In this model, the nine responses were dichotomous dependent variables, while setting, type of differentiation, and their interaction, as well as the responder characteristics mentioned earlier, acted as independent variables. We treated the nine responses as within-participant repeated measures. All analyses were done in SPSS 20. A significance level of 5% was used in all analyses.

Results

Differentiation – Setting and Type

Table 1 shows the overall number and percentage of participants agreeing with access differentiation in each of the three health care settings, and for each of the three types of differentiation. As Table 1 shows the percentage in favour of differentiation varied between 20% and 58%, a substantial proportion of participants.

The type of health care setting, the type and form of differentiation, and the interaction between setting and differentiation all had significant effects on the proportion agreeing with differentiation. In general, more participants were in favour of giving a premium discount to those with positive health behaviour than there were supporters of co-payment for those with negative health behaviour. Higher proportions of differentiation were seen for smoking than for participation in screening, and still higher for smoking cessation in COPD patients.

We also observed a significant interaction between setting and type of differentiation. This is most obvious for lung cancer, where more than half of the respondents were willing to agree with a premium discount for non-smokers, while only one in four would agree with co-payment for smokers, and about one in three with assigning different places on the waiting list.

Table 1 Number and proportion of participants that agree with differentiation based on health behaviour

<table>
<thead>
<tr>
<th></th>
<th>Colorectal Cancer</th>
<th>Lung Cancer</th>
<th>COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discount</td>
<td>967 (33%)</td>
<td>1600 (54%)</td>
<td>1661 (56%)</td>
</tr>
<tr>
<td>Co-payment</td>
<td>602 (20%)</td>
<td>767 (26%)</td>
<td>1323 (45%)</td>
</tr>
<tr>
<td>Waiting list</td>
<td>981 (34%)</td>
<td>1110 (38%)</td>
<td>1697 (58%)</td>
</tr>
</tbody>
</table>
Table 2  Preferences for differentiation in health care in subgroups of participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Average agreement</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1279 (56%)</td>
<td>45%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Female</td>
<td>1652 (43%)</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td>0.46</td>
</tr>
<tr>
<td>50-54</td>
<td>581 (20%)</td>
<td>44%</td>
<td></td>
</tr>
<tr>
<td>55-59</td>
<td>798 (27%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>685 (23%)</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>65-69</td>
<td>511 (17%)</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>70-74</td>
<td>356 (12%)</td>
<td>46%</td>
<td></td>
</tr>
<tr>
<td><strong>Smoking</strong></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Current smoker</td>
<td>437 (15%)</td>
<td>51%</td>
<td></td>
</tr>
<tr>
<td>Former smoker</td>
<td>1491 (51%)</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>Never smoker</td>
<td>1000 (34%)</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
<td></td>
<td>0.65</td>
</tr>
<tr>
<td>Yes</td>
<td>2412 (82%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>514 (17%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td><strong>Disease</strong>****</td>
<td></td>
<td></td>
<td>0.75</td>
</tr>
<tr>
<td>Yes</td>
<td>880 (33%)</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2066 (70%)</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
<td>0.28</td>
</tr>
<tr>
<td>High</td>
<td>1840 (63%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>969 (33%)</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
<td>0.86</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2610 (89%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>Elsewhere</td>
<td>332 (11%)</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td><strong>Grade current health</strong></td>
<td></td>
<td></td>
<td>0.11</td>
</tr>
<tr>
<td>1 - 5</td>
<td>103 (35%)</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>6 - 10</td>
<td>2815 (96%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td><strong>Illiterate</strong></td>
<td></td>
<td></td>
<td>0.15</td>
</tr>
<tr>
<td>No</td>
<td>2829 (96%)</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>97 (3.3%)</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2946</td>
<td>40%</td>
<td></td>
</tr>
</tbody>
</table>

*Lower education: Only primary school as highest level of education
** Percentages do not always sum to 100% because of missing responses
*** p value for the corresponding effect in the multivariable general linear model
**** Cardiovascular disease, COPD, Cancer, diabetes at the time of answering the questionnaire.
Differentiation – Personal characteristics

Table 2 shows the participant characteristics, the average proportion willing to differentiate over all nine situations combined, and the corresponding p-value in the hierarchical general linear model. As this was a multivariable analysis, the effects are conditional on the other characteristics listed. As can be appreciated from the table, males were significantly more in favour of health care differentiation based on health behaviour than females, as were non-smokers, compared to smokers. In contrast, no statistical differences were observed between respondents with or without disease, between age groups, or between subgroups defined by level of education, country of birth, marital status, having children, health literacy, and personal perception of health status.

Discussion

Limitations

A number of methodological issues need to be addressed. Our study group was a convenience sample from participants in a pilot colorectal cancer screening program. Participation in the questionnaire study was high, with a 71% response rate. As all of our respondents had previously agreed to participate in screening, we cannot generalize our findings to the Dutch population of the same age range. As these participants had completed colon cancer screening, they might be more in favor of prevention in general and measures stimulating life style changes than their counterparts who did not participate in screening. Yet most characteristics of the respondents in our study, such as smoking behavior, are in line with those reported elsewhere for Dutch society at present. The age and sex distribution were also similar to that of all screening participants. The screening invitation was sent to persons over 50 only; it is possible that younger people have different, more positive, views about differentiation in health care. The nine hypothetical situations were not randomly arranged; they were presented in a single, fixed order to all participants, so we cannot exclude some order effects in our results.

General discussion

In this study we explored views on differentiation in health care according to health behaviour, across a number of health care settings. We observed that a substantial proportion of respondents were in favour of differentiation, though there were differences based on setting and type of differentiation, and differences between subgroups defined by participant characteristics. Males and non-smokers were more frequently in favour of differentiation.

There is a growing societal debate on differentiation in health care. A number of studies...
on the views and choices of lay people have been conducted so far. Van der Star et al. evaluated the willingness to pay for inclusion of a treatment in the basic insurance for a hypothetical lifestyle dependent and lifestyle independent health problem. They concluded that there was a preference in their sample towards the latter type of health problems. Gollust and Lynch conducted a study in which three experimental vignettes concerning health and health care were used to explore choices in differentiation in health care. They found that cues about the behavior of sick individuals exert a more powerful effect on health policy opinions than racial or class group cues. The last two issues are traditionally important in US society. A more individualistic health attitude seems to be associated with increased support for individual rather than societal responsibility for health care costs, as the authors conclude. This has been mentioned before by Schnabel, who emphasized that rapid social development is taking place, in which a more quantitatively oriented system is changed into a more qualitative, individualistically oriented system. With this in mind the public opinion is changing; increasingly individuals need to take care of their own health care needs. Promberger studied financial incentives in UK and US participants and concluded that the acceptability of financial incentives has increased with the effectiveness of the incentive. Schmidt conducted a study in which survey data was used to assess reward and penalty based incentives. The authors found that some support for penalizing unhealthy behavior, with reward-based incentives being favored over penalty based ones, in line with the outcomes of our study. Schmidt and colleagues observed that the size of penalties acceptable to the survey participants was comparatively small, much smaller than some of the wellness incentives and penalties used by US employers. The authors warned that these incentives matter on ethical grounds, as it cannot be assumed that it is equally easy for all to meet health targets to secure a benefit or avoid a penalty. There is a risk of inequity that would further disadvantage the people most in need of health improvements. Programs should be designed to engage, not to frustrate those most in need of health improvement. Dolan and Tsuchiya conducted a survey in which individuals were interviewed about their views about (in)equalities in society. The authors observed that individuals considered the extent to which individuals can be held responsible for those inequalities as decisive for their judgment. In other words, respondents are most willing to penalize those who they consider most responsible for their health status.

Schokkaert indicated that the notion of control plays an important role in the extent to which individuals are to be held responsible for their behavior. It also seems that the level of control is important in the choice of consequences; our results show a tendency to assign more consequences to behavior that is within control of the individual, such as smoking. Further studies could address the exact motives for the answers participants
gave to our questions. In focus group discussions, one could confirm or refute the motives for agreeing or disagreeing with differentiation.

At present, Dutch society, government and policies present a mixture of egalitarian and libertarian beliefs. The health care system is based on solidarity, though there is a strong emphasis towards more libertarian measures. Cappelen and Norheim189 explored arguments for assigning limited but significant roles to individual responsibility in the design of the health care system, from a liberal egalitarian perspective. They conclude that it is possible to assign a role to individual responsibility in the rationing of health care resources. There is now a shift in the Dutch health care policy towards instruments with a stronger emphasis on personal responsibility.11 Individual responsibility can increase personal autonomy, by empowering individuals to arrange health care towards their personal preferences. Though, as ter Meulen and Maarse argue, weaker groups who are unable to take this responsibility need to be protected.11 12

One of the solutions for maintaining solidarity in health care, while at the same time increasing the dual principle of solidarity, would be a bonus-malus system, which alternately rewards (bonus) or penalizes (malus). Such mechanisms are used in several insurance systems. An alternative could be to use an algorithm in deciding which interventions will be in the basic benefits package system, with personal responsibility such as smoking behaviour as part of the algorithm.413 This system though should not lead to total exclusion from care.

In conclusion our study confirms that part of the Dutch public, especially those who participate in colorectal cancer screening, is in favour of some form of financial differentiation in the distribution of health care. Some favouritism could be seen in smokers, while individuals also seem to make differences according to the level of control they perceive for others in specific situations. Our study can be used in the ongoing debate about solidarity and behaviour in health care, if only because it shows the risk of in-group favouritism, which could also be present amongst scholars and policy makers.
References


