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Abstracts

The Risk of Home Care Dependency: Caregiving Experiences and Preparation in Women and Men Between 18 and 79

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Keywords: home care dependency, caregiving experiences, family care, attitudes, expectations, preparation

Summary

An ever-growing number of people in Germany are today confronted with the issue of home care dependency. The article examines the degree to which preparations for the possibility of future care requirements have been changed by the fact that an increasing number of people are impacted by or have experience with the issue of home care. Moreover, it examines the degree to which people in Germany feel themselves to be well-informed on the issue of home care, and shows that informedness levels have significantly increased in a 10-year comparison. Finally, questions of attitudes and expectations with regard to familial support will be addressed. Here, it becomes evident that the family will continue to play a central role in the provision of help and care.

Background and inquiry

The assumption being examined was that the increasing confrontation with the risk of becoming care-dependent has led today's aging generations to changed behavior with respect to preparatory behavior and insurance for home care. This was operationalized through the following questions:

- Has the degree to which the German population is well-informed on the issue of home care changed?

- To what extent do experiences with care influence attitudes and opinions toward family-provided care?
- From whom do women and men in Germany expect to receive support in their old age?
- How do survey respondents' assess their own preparations for the eventuality of becoming dependent on care?
- Along which aspects of preparation are men and women of different age groups distinguished?
- How has willingness to make private preparations for the risk of becoming dependent on care developed?

Methods

A total of 895 women and 900 men (n = 1,795) between the ages of 18 and 79 were interviewed in December 2012. Analytical methods included descriptive statistics, correlation analysis and regression analysis.

Findings

The initial findings show that a very high proportion of respondents have already come into contact with the issue of home care. One-fifth had themselves provided care or were currently doing so. The group of current or former caregivers can be characterized as on average more likely to be older (over 50), female, to have a secondary- or primary-school education, and to be either married or widowed. A high degree of experience with the issue correlates with a significantly higher degree of informedness. Thus, the share of those who felt themselves to be well or very well informed on the issue of home care has significantly increased in the last 10 years, from 48 percent to 72 percent. The fact that the issue has pervaded the public mind through more frequent personal involvement in care and better informedness also influences attitudes to various service constellations in the eventuality of personal care needs. On the one hand, family-provided care has an extremely strong position, with expectations remaining stable and high that the immediate family will provide care functions if possible. On the other hand, this stance is increasingly being expanded by attitudes that consider the involvement of professional service providers to be an acceptable home care alternative. These developments have not yet led to a widespread readiness to secure insurance against the risk of becoming dependent on home care. Thus, a large majority are

willing to pay either no or only minor additional monetary premiums toward future home care. At the same time, 42 percent of respondents rated their own provisions for future care needs as poor or very poor.

Conclusions

The findings show that an increasing number of women and men are making provisions for their old age. Financial aspects are often emphasized, but issues of housing and the provision of care in old age are also important. However, it must also be inferred that in the future, an appropriate level of service provision once becoming dependent on home care will depend only partially on personal experiences, expectations and attitudes. An essential role will also be played here by the further development of the policy and societal framework for home care, such as the long-overdue redefinition of what it means to require home care, the associated practical expansion of services, and the ultimately inevitable increases in financial provision for public and private home care insurance.

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What does the public know and think about Alzheimer's and other dementia disorders?

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Keywords: Alzheimer's, dementia, knowledge, attitudes, reactions, public

Summary

In the autumn/winter 2012 Gesundheitsmonitor survey, about half of the 1,795 respondents reported having had personal contact with somebody suffering from dementia – mostly within family circles. Dementia is perceived as a personal threat, and people with dementia as unsettling. Nevertheless, the willingness to care for and nurse people with

dementia is high. Early detection also commands very strong levels of approval. Social factors such as gender, education level, age or previous care experiences show moderate to low correlations with knowledge about and personal attitudes toward dementia and its sufferers.

Background and inquiry

Dementia disorder, which affect about 1.5 million people today, represent one of the greatest challenges facing society. These numbers will continue to climb in the coming years as a consequence of demographic change. Four groups of questions in the august/winter survey of the Gesundheitsmonitor 2012 were aimed at capturing the mood of the population on the issue of dementia and the following aspects:

- Experience with dementia and those suffering from its effects;
- Emotional reactions to Alzheimer's/dementia;
- Knowledge about Alzheimer's/dementia; and
- Attitudes to Alzheimer's/dementia, as well as to dealing with them.

Methods

Data is drawn from the responses of a representative sample of 1,795 insured individuals in the context of the yearly Gesundheitsmonitor survey (autumn/winter 2012). Responses were evaluated descriptively and on the basis of inferential statistics, as well as subjected to comparative subgroup analyses.

Findings

Experience: 45% of respondents indicated that they had previously had contact with people suffering from dementia. Among this group, 71% had encountered the issue within their family circle, while about one in four (27%) had previously cared or was at the time of the survey caring personally for a person with dementia. While women tend to have more contact than do men (48% compared to 42%), the gender difference with respect to the provision of care is surprisingly small (28% to 26%).

Reactions: About half to a quarter feel discomfort, uncertainty or even fear in the presence of dementia sufferers. This share is significantly lower among those with care experience. Nevertheless, prosocial attitudes such as sympathy, compassion and the urge to help are quite pronounced, with 59% to 84% support.

Knowledge: The prevalence of dementia disorders is correctly estimated by a third of respondents. The great majority can indeed properly describe the main symptoms of Alzheimer's, although with specific aspects of dementia command little familiarity. In addition, the possibilities for clinical diagnostics and treatment are in some cases significantly overestimated.

Attitudes: With respect to attitudes to dementia, three-quarters feel the idea of contracting dementia themselves to be a threat, and 97% regard living with a dementia sufferer to be an extremely significant burden. Early diagnosis is supported by 92% of respondents. Eighty-one percent are ready to care for family members suffering from dementia at home, although more than half regard a nursing home as a better option. Overall, the attitudes of those who have had no contact with dementia sufferers are both more negative and more pessimistic than the attitudes of those with contact or caregiving experiences.

Conclusions

For the most part, the population responds to dementia sufferers sympathetically and empathetically. Dementia as such, however, is perceived as threatening and unsettling. This can exacerbate the stigmatization of sufferers, increase their social distance, and contribute to their feelings of shame and concealment. Education campaigns and public discussion on the issue of dementia are still needed.

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Attitudes toward organ transplantation and donation

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Keywords: willingness to donate organs, donation willingness, consulting with relatives, trust, organ transplantation, organ donor card

Summary

Building on Gesundheitsmonitor 2011 findings on the willingness to donate organs, this paper will examine how the incidence of organ donation in Germany can be improved. To this end, insights are developed with respect to decisions to donate organs following one's own death, as well as potential decisions made through consultation with relatives after the death of a near relation. Also compiled will be the degree to which survey respondents are informed about transplantation procedures, their attitudes, and their intended or already realized decisions with respect to postmortem organ donation.

Background and inquiry

The paper addresses three issues central to the incidence of postmortem organ donation.

In the current context, in which irregularities in the allocation of organs in some transplantation centers have become known, the importance of trust in the processes of transplantation medicine is examined.

The question of which population groups tend to agree to postmortem organ removal or have an organ donor card is investigated.

In addition, survey respondents are asked how they would react if forced to decide on the extraction of a deceased relative's organs, and their answers compiled.

Methods

As a data resource, the study draws on the information from a representative sample of 1,795 insured individuals from the annual Gesundheitsmonitor survey for 2012. Analytical methods include descriptive statistics, correlation analysis, and binary and ordinal logistic regression.

Findings

As previously, trust in transplantation medicine processes is by far the most important aspect in explaining respondents' attitudes toward organ donation and their own willingness to donate. For a higher level of consent to organ donation, trust in organ removal processes as well as in the allocation of transplants is essential.

At about 20 percent, the documented willingness to donate organs remains at about the same level as in 2011. In contrast, the willing-

ness to donate organs among those who do not yet have an organ donor card has declined in the last two years.

With respect to family consultation, family members are shown usually to follow the wishes of the deceased if these are documented or at least known. If the deceased's intentions are unknown, a relative's own willingness to donate organs appears to have an influence on the organ removal decision.

Conclusions

An increase in the prevalence of organ donor cards can only be expected if trust in the allocation procedures is reestablished. This would also strengthen overall confidence in transplantation medicine procedures.

Since family members generally abide by the will of the deceased, it would be desirable for families to engage in conversation about decisions to be made during illnesses and before and after death. Written information from health insurance organizations in the context of »non-mandatory, nudged declarations of donor intent« could contribute to this end. As a more intensive and personal type of information, an individual medical consultation, possibly with the participation of family members, would also be possible.

In parallel, improving transparency by producing reports on organ allocation processes, ensuring that implementation complies with rules, and engaging in strict oversight could help restore lost trust.

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Care for ADHD in the transition to adulthood from the perspective of those affected

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Keywords: attention deficit hyperactivity disorder (ADHD), transition, adolescence, adulthood, care, drug treatment, therapeutic aids, survey

Summary

By means of a survey of insured individuals aged 18 to 21 with a diagnosis of ADHD in their youth, the share of those with persisting symptoms is ascertained, and an assessment of needs after the age of 18 is performed.

Background and inquiry

ADHD is a disorder that appears in childhood and adolescence. As yet, there is little information available on the persistence of symptoms after the 18th birthday, or on patient care during the transition from adolescence to adulthood. A survey of young adults affected by ADHD in their youth enables the collection of information on and experiences with therapies carried out in respondents' youth, their current conditions and continuing presence of typical ADHD symptoms, and their experiences with ADHD-specific therapies after the 18th birthday. Of interest here is whether offers of assistance or a continuation of therapy after the 18th birthday have been discussed, and whether those who reported psychological stress as young adults have made use of therapeutic help.

Methods

A written survey of 3,727 BARMER GEK-insured individuals (3,075 men, 652 women), primarily between the ages of 18 to 21 was carried out, targeting those who had received at least two verified ADHD diagnoses before their 18th birthday. A subsequent 623 responses were returned (response rate: 17%). The survey consisted of 28 questions with various options and opportunities for open-ended responses. The analysis was performed using descriptive statistics. Regression analyses were carried out in order to examine potential relationships between variables.

Findings

Patients participating in the survey had primarily been treated with drugs: 94% had received methylphenidate and/or atomoxetine. Those who had been diagnosed before the age of 11 had a significantly higher chance of having been treated with stimulants. Slightly more than half of the respondents (57%) indicated that the drug-based therapy was conducted for more than three years. Nearly 30% to 50% indicated that as a result of the drug treatment, they had managed better

in school (37%), achieved a better performance (48%) or felt significantly better overall (27%). However, a comparable share also described having perceived unwanted side effects (sleep disturbances, decreased appetite). Asked about their current situation, 37% report the continuing presence of severe to very severe problems typical of ADHD. Twenty-eight percent agree with the statement that ADHD is still important in their life today. For about 50%, drug-based treatment was continued after their 18th birthday; however, there is evidence that it was difficult to get an appointment with a therapist. About half of those who according to their own statements are still affected by severe symptoms are not in therapeutic treatment for this purpose.

Conclusions

The findings of this paper show that a significant proportion of ADHD patients suffer from symptoms even in early adulthood, and continue to need therapeutic help. The passage from youth to adult care should be prepared in a timely and targeted way (a key idea here being that of transition). The establishment of consultations for young adults dealing with child, youth and adult psychiatric issues represents a first important measure. Overall, awareness of the problems associated with the persistence of ADHD into early adulthood should be raised among primary care physicians.

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The transfer of medical tasks: Patients' expectations regarding the use of paramedical services to reduce care bottlenecks

Michael Wessels

Keywords: delegation, substitution, pilot projects, transfer of medical tasks, medical task transfer, Advanced Nurse Practitioners (ANP), Advanced Practice Nurses (ANP), ensuring care

Summary

The transfer of medical tasks has long been a controversial subject. Given current gaps in the provision of care and a lack of trained health care personnel, the transfer of medical tasks is discussed as a possibility for ensuring supply. With the Home Care Development Act (§63 Paragraph 3c SGB V), the legislature made possible pilot projects for the transfer of medical tasks to specially trained nurses. The transferable activities and required qualifications have been specified by the Federal Joint Committee (G-BA) in an associated directive.

Previous surveys have found patients to regard the transfer of medical tasks rather skeptically. However, it was assumed that patients' reservations would be diminished and acceptance levels increased if they were to have genuinely positive experiences, as for example in the form of shorter waiting times and improved accessibility. The validity of this assumption is assessed in this paper.

Background and inquiry

A survey was conducted on the expectations and concerns of patients with respect to the transfer of medical tasks, the results of which are used to assess the following hypothesis: Previous experiences with paramedical (health care) services have a significant influence on patients' acceptance of the transfer of medical tasks.

Methods

For the Gesundheitsmonitor 2013, a special survey of 1,817 individuals insured through BARMER GEK was conducted. The total sample ($n = 1,817$) is divided into an experimental group and a control group. The experimental group ($n = 817$) is limited exclusively to those insured individuals who have had experience with medical services recommended by a doctor being provided by a paramedical service provider, specifically in the context of medical service transfer. Descriptive statistics and nominal regression models were used as analytical methods.

Findings

The analyses show that acceptance of medical service transfer is significantly influenced by previous experiences. If insured individuals have had positive experiences, they generally regard the transfer of medical responsibilities favorably. The size of the city or town of resi-

dence was identified as a second factor influencing acceptance of medical service transfer. Different levels of acceptance of medical service transfer also derive from regional differences in the density of supply. A lower density of supply is correlated with a higher level of acceptance of service transfer.

Conclusions

Insured individuals view the transfer of medical tasks as an adequate measure for the prevention of supply shortages. With this in mind, all stakeholders (lawmakers, physicians, nurses, health insurance organizations) should push ahead with the implementation of pilot projects in the transfer of medical tasks with more emphasis than in the past.

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Finance reform in health insurance. Public appraisals reflected in concrete reform scenarios

Martin Albrecht, Jan Böcken

Keywords: Health insurance, financing reform, assessment, population, justice, reform needs

Summary

Justice deficiencies and reform needs are perceived by the population more strongly on the services side than in the financing of health insurance. Accordingly, the services-side justification for integrated health insurance – equal doctor fees and waiting times for all patients – meets with comparatively high popular support. On the financing side, reform approaches are preferred that the majority regards as likely to impose few concrete burdens for itself. Younger people show themselves to be considerably more skeptical with respect to principles of solidarity in the financing of health insurance.

Background and inquiry

Among experts, the debate over an integrated health insurance market is animated, and at least in the relevant professional media, conducted openly. By contrast, the assessment of the general population is not well known, although larger changes completely without popular support hardly appear feasible. Therefore, in the present article, aspects of justice, principles of solidarity within health insurance, and key starting points for the reform of the health insurance system will be analyzed from the perspective of the public. Moreover, the question is asked what implications for future health-policy reforms may arise from the public's opinions, and how the population's preferences are to be assessed if the public is presented with expected financing effects associated with specific reform scenarios.

Methods

Data is drawn from a representative survey of the adult population from 18 to 79 years of age, conducted in Nov./Dec. 2012 with a written, mail-distributed questionnaire. Results were calculated for frequency counts with weighted data, and weighted on the basis of income and education variables. Multivariate techniques (nominal regression) were used on the basis of unweighted data.

The evaluation and discussion of determined population preferences takes place under the consideration of the results of a study that calculated the financing effects of specific reform scenarios on the basis of microdata simulations.

Findings

High levels of support were found in the population particularly for reform approaches on the services side. There, a majority of respondents saw justice deficits with a higher need for reform (differences between doctor's fees and appointment availability between publicly and privately insured patients) than was the case for financing. On the financing side, the highest level of support was given to reform approaches that the majority of respondents presumably associated with little concrete personal burden (integration of the formerly privately insured into the public system, increase in state subsidies). Younger people expressed lower levels of support for many reform approaches, and showed more reserve with respect to fundamental questions of solidarity-based financing in the health sector.

Conclusions

The services-side rationale for an integrated health insurance program – equal doctor fees and waiting times for all patients – meets with significant support among the general population; by contrast, the financing-side justification for expanding the insured population appears somewhat more difficult, because tangible benefits for a large population share are not expected. Less public opposition is likely if additional burdens manifest only indirectly or are not explicitly observable, perhaps in the form of an expansion of joint financing or an increase in tax subsidies from the general tax revenues without a specifically identified cost to other programs. The question of whether and how intergenerational redistribution in health insurance will change should be given more attention in the creation and communication of any future financing reform.

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Co-payments in the German Health Care System: Size, Determinants and Consequences for Medication Use

Patrick Bremer, Dirk Sauerland, Ansgar Wübker

Keywords: co-payments, prescription drug avoidance, financial stress, chronically ill

Summary

This article examines whether and how co-payments affect the utilization of prescribed medications. The findings show that people with low incomes as well as the chronically ill more often resort to self-medication, independently reduce a medication's dosage, or put off or even wholly avoid filling prescriptions ordered by a doctor. All behaviors can be observed most frequently in those with acute health complaints. It seems advisable to redesign existing co-payment exemptions in order to make it easier to access necessary medical care, especially for the group of the chronically ill and low-income people.

Background and inquiry

The financing of health care services through co-payments is always a subject of public and health-care policy debates. Critics fear that co-payments, particularly for low-income individuals with a high need for health-care services, will become a barrier to access for necessary medical care, and thus potentially lead to protracted illnesses. Proponents see co-payments as an adequate instrument through which to strengthen individual citizens' personal responsibility and cost-consciousness. They hope for a steering effect producing better allocation of resources within the health care sector.

Within the German health care system, insights as to the effect of co-payments are focused on the consultation fee abolished on January 1, 2013. However, the effect of co-payments in other service areas remains unclear. In particular, previous research has not examined whether co-payments for pharmaceuticals influence the utilization of prescription medications. Specifically, therefore, the following issues will be examined:

- Whether and what forms of co-payment-related reductions in demand occur (such as the failure to fill prescriptions, self-medication or taking reduced dosages of medication);
- Which individual factors are associated with these behaviors; and
- Which health conditions result in a reduction in demand.

Methods

The 21st Gesundheitsmonitor survey serves as the source of data. Along with detailed social, demographic and disease-related information, this dataset provides a specific set of questions on the size and consequences of co-payments. The sample consists of 1,795 individuals between the ages of 18 and 79. The statistical evaluation is performed with the help of a descriptive comparison of means and multivariate regression analyses.

Findings

A significant proportion of respondents use various methods to avoid co-payments for prescription medications. Thus, 10 percent of all respondents have avoided filling a prescription in the last year; nine percent have reduced the dosage; 10 percent have postponed filling the prescription; and 29 percent of respondents have resorted to using home remedies or expired or non-prescription medications (OTC

drugs) instead. The probability of these behaviors occurring is significantly higher among low-income and chronically ill people. Each of the four behavior patterns was adopted most frequently in cases of acute health problems, and second-most frequently in cases of high blood pressure.

Conclusions

The findings encountered here show that co-payments significantly reduce the demand for health care services. Crucial to note here is the fact that chronically ill people in particular, meaning persons with a particularly high need for pharmaceutical-based care, reduce or postpone their usage of medication significantly more often. Furthermore, the observed interference with the use of medicine for high blood pressure, high cholesterol and diabetes runs the risk of long-term negative health consequences and protracted illnesses. With this in mind, it seems advisable to redesign existing co-payment exemptions in order to make it easier to access necessary medical care, particularly for the group of the chronically ill and low-income persons.

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Criteria and procedures for the prioritisation of medical services: Results and methodological challenges

Heiner Raspe, Sabine Stumpf

Keywords: prioritization in medical care, prioritization criteria, public survey, citizen opinion

Summary

This paper addresses citizens' attitudes and preferences with respect to criteria and procedural rules in the prioritization of medical care. In addition, sociodemographic and health-related variables are examined as potential explanatory factors for variation in the responses. A focus is placed on prioritization criteria evaluated in previous surveys

as being controversial or inconclusive. Results are discussed critically in the light of these previous studies.

Background and inquiry

Prioritization in medicine has to date been discussed in Germany primarily within professional circles. This is also true of the debate over any prefixed goals, ethical principles and criteria as well as procedural issues. However, it is essential here to listen to citizens as well; in these matters, they have as much weight as the various groups of professionals and academics. This article thus addresses the following questions:

1. From a citizens' perspective: What are the desirable/unacceptable criteria for prioritization in medical care? What groups of actors should develop or at least participate in an advisory role in the development of prioritization proposals?
2. Can response variation in the assessment of prioritization criteria be explained through sociodemographic or health-related variables?
3. How do the results of this paper comport with those of earlier national and regional public surveys?

Methods

The data from the 21st Gesundheitsmonitor survey (autumn 2012 survey; return rate: 78%) serves as basis for the statistical analysis. Analytical methods include descriptive statistics, formation of ranked lists, logistic regression, configural frequency analysis and hierarchical cluster analysis.

Findings

The highest degree of support was seen for the preferential treatment of children with severe diseases (87%), imposing sanctions on patients with health-endangering lifestyles or behaviors through additional payments or additional private insurance (77%), as well as special consideration for patients in difficult social or financial situations (73%). Preferences ("getting a doctor's appointment faster") for patients with professional responsibility for others, by contrast, were rejected by a majority (81%), as were preferences for patients that perform volunteer work (66%) and the use of less-expensive treatments that are more unpleasant for the patient (63%). In another question, however, the consideration of cost-benefit ratios for a reimbursement

of services through the statutory health insurance was less restrictively assessed.

The attempt to identify explanatory factors for the variation in responses brought few significant or relevant variables to light. Similarly, the analysis of possible response patterns (clusters) did not yield interpretable results.

In the question of which professional and individual groups should participate in the prioritization, doctors were named first by a long distance. Health insurance plans, medical researchers, and hospital managers followed. In the opinion of a majority, academics from other disciplines, the pharmaceutical industry, but also foundations and civic associations as well as churches and religious communities should not be involved in the process of prioritization.

The comparison with previous surveys shows some consistent appraisals, particularly in the assessment of potential decision-makers in health care; however, some unclear or inconsistent response tendencies point to the methodological sensitivity of the survey results, and thus to methodological difficulties of survey-based investigations of prioritization questions.

Conclusions

The analyses of the data from the 21st Gesundheitsmonitor complement, confirm, clarify and correct the findings of earlier public surveys on the classification of medical services. They warrant and support an urgent, targeted and more developed national discussion. In addition, they raise a number of methodological questions.

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