The needs of caregivers[1]

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ABSTRACT

This paper identifies the needs of caregivers, i.e. those who provide help to senior members of their families who are dependent and cannot perform the activities of daily living. Results are based on an explorative study that was conducted in 2017. The research used in-depth interviewing with 62 main caregivers. Altogether 76 different needs were identified and these needs were subsequently clustered into nine categories and described in detail. The identified needs may serve as a source of criteria for evaluating prospective interventions aimed at caregivers.

INTRODUCTION

Satisfying the needs of caregivers who provide care to dependent senior members of their families is important from the perspective of quality, extent (scope) and adequate targeting of the care. There are many studies that focused on the needs of seniors (Detmar et al. 2001; Strawbridge et al. 1997; Ingleton et al. 2003; Proot et al. 2004 or Sieget 1991). Within this strand of research there are similar studies from Czechia that took local determinants and characteristics into account (e.g. Sýkorová 2005; Jeřábek 2009; Kuchařová 2002, Rabušic a Vohralíková 2004; Veselá 2002). Although satisfying the needs of seniors who are recipients of the care is the primary focus of many interventions in this field, it is equally important to pay attention to the needs of those who provide the care, i.e. caregivers. It can be argued that meeting caregivers' needs is a necessary precondition for satisfying the needs of dependent seniors. It is also important for caregivers' quality of life, their health, capacities to provide care and for the sustainability of their performance during the whole course of the care. Overlooked needs of those who provide care might increase the burden associated with the care, decrease caregivers' performance, and result in lower overall quality of the care. Therefore, finding the ways to meet caregivers' needs is important not only for caregivers themselves but for seniors as well.

Knowledge about caregivers' needs is not only important at the micro level where it impacts the individual caregivers and care recipients. It has a great value even at the macro level as well because such knowledge enables relevant and adequate interventions to be prepared and makes them evaluable. It is barely possible to evaluate the relevance and usefulness of such interventions without detailed knowledge about caregivers' needs. As a matter of fact, interventions should not even be proposed without such knowledge.

The importance of the caregivers' needs is reflected by an increasing number of studies. However, in spite of the accelerated interest of researchers in the topic, caregivers' needs are still not described in detail comparable with the needs of dependent seniors. Some of the previous studies focused on caregivers' burden and searched for the relevant factors determining such burden (Aranda 1997; Connell and Gibson 1997; Mastrian et al. 1996). Other researchers paid attention to barriers and issues

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associated with caregiving (Gallagher et al. 1989; Shaw et al. 1997; Schulz and Beach 1999) and further studies focused on preferences and wishes of caregivers (Levine 1999; Martire et al. 1997; Ory et al. 1999). A substantial part of researches turned their attention to caregivers who look after seniors requiring medical treatment; in this respect, attention is paid especially to elderly oncological patients that are staying within the family environment (Shin et al. 2010, Given et al. 2001, Bart 2006 or Cho et al. 2006). Attention is further paid to the needs of seniors with Alzheimer disease and their caregivers (Hall 1987, Mittelman 2004, Parren et al. 2006 or Thompson 2006). However, there is a lack of knowledge about other types of caregivers and their needs.

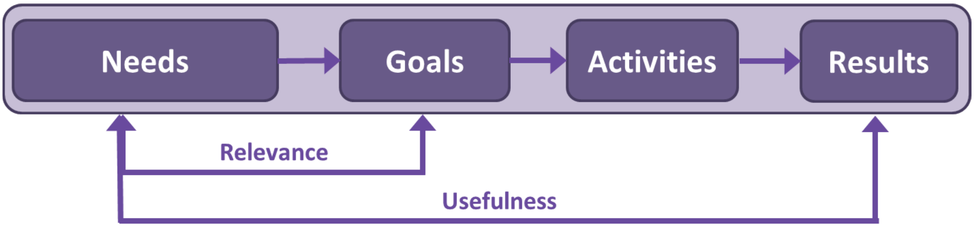
The objective of this paper is to provide a systematic review of empirically identified needs of caregivers who provide informal family care to dependent senior members of their families. Based on an explorative study, a typology based on the merit of those needs is presented. For each type of needs, typical approaches for their satisfaction taken by caregivers are described. Such analysis shows the most urgent areas that caregivers cannot solve on their own or with the help of other family members and call for interventions.

THE CONCEPT OF NEEDS

J. McKillip defines needs as the difference between "what is" and "what should be" (McKillip, 1987). This approach was further elaborated by Witkin and Altschud (1995) who defined needs as the difference between the current and optimal state. However, apart from this rather normative concept there are some other approaches to defining needs. For instance, Davis defined need within health care as a subjective feeling initiating the decision-making process concerning the use of resources in order to satisfy the need (Davies 1955). Similarly, Baldwin (1998) considered needs as an attempt to compensate for the dis-equilibrium.

Gupta (2007), Witkin and Altschud (1995) or e.g. Soriano (1995) pointed-out the merit of needs that differ from preferences, wishes or wants. Similarly, Bradshaw (1994) considered wants and wishes as a special category. The fact is that in some real-world situations, needs and wants might merge together, however, from conceptual point of view, it is essential to consider the two constructs separate. The reason why it is important to conceptually differentiate needs from wants, even in the field of caregiving, is that many caregivers cannot identify their needs because they are not aware of what they are lacking. On the other hand, identifying their preferences or wants is easier because they are conscious and are reflected by caregivers. McKillip in this respect emphasized that individuals do not know what they might need (McKillip 1987).

From the perspective of social interventions financed from public budgets, it is essential to design and implement only such interventions that have the capacity to satisfy the needs of the given target group. The reason is that only such interventions might help to relieve the given issue. Thus, the needs serve as a source of key indicators informing (either ex-ante, or ex-post) about the relevance of the given interventions (Berk, Rossi 1999). The intervention is considered relevant once its goals satisfy the previously identified needs.



SCHEME 1 — The significance of the needs

As scheme 1 shows, the needs can also help to evaluate the usefulness of intervention by comparing the achieved results (typically outcomes) with the needs (Donaldson et al. 2009). The intervention is considered useful when its outcomes meet the needs of the target group (or other relevant stakeholders). Putting the needs and wants into one basket might have distracted the focus of such intervention (or its evaluation) and provide biased feedback.

From another perspective, one can distinguish different types of needs. In this respect, Altschud and Witkin (2000) discriminate outcome needs from treatment needs. The merit of outcome needs is represented by the gap between the current and optimal state. On the other hand, treatment needs refer to the ways in which the needs may be met. Therefore, treatment needs are associated rather with the measures or process of satisfying the needs, whereas outcome needs reflect their merit. In spite of this difference between the two, it is important that treatment needs are congruent with outcome needs. For instance, as an outcome need, the awareness of manipulation techniques with seniors might be identified; attending specialized training course would then be the corresponding treatment need. In practice, there are situations when only treatment needs are identified but the evidence of a corresponding outcome need is missing. In the above mentioned example, there would be a need to perform the training course, however, the low awareness of caregivers about manipulation techniques with seniors would not be proven. Such intervention then might be evaluated as self-serving.

Many researches (Reviere et al. 1996; James 1999 or Crown 1991) point out that there are many routes and methodological options how the needs might be identified and assessed. These approaches include epidemiological studies, comparative tasks and verbal reports (i.e. declared needs). The presented study identified caregivers' needs with a comparison of the individual self-reported descriptions of the daily routines associated with the care, practices and relevant circumstances. An explorative type of study was performed in order to gain information on "what is". Each respondent was therefore asked to describe the usually performed activities concerning the care, its reflection and dynamics. Interviewers were also instructed not to ask what respondents would prefer or want with relation to the care. Therefore, there were neither questions on what the caregivers prefer, nor the identification of their wants. Instead, a detailed description of the given practice was asked because only such information might be used as a source of information about needs, i.e. about the gap between the real situation and an optimum. Such a tactic of in-depth interviewing corresponds with methodology of identifying needs.

Subsequent analysis of the narrative descriptions focused on identifying the individual activities and comparing such practices of the given case with the ways how other respondents perform the same tasks. Taking this approach, the optimal state, i.e. "what should be", was defined and thus the identification of the needs was enabled. Furthermore, attention was focused on comparing the approaches to solving a given part of the care with the aim to identify treatment needs and distinguishing them from outcomes needs.

DATA ANALYSIS

In-depth interviews were conducted with the main caregivers in given households during the year 2017. A qualitative approach prompted the exploratory attempt of the research objective and enabled the respondents to elaborate on their experiences. During the interviews, it become obvious that many caregivers considered the topic sensitive and therefore they appreciated the set research design where they could talk with interviewers alone without other persons following the discussion.

Altogether 62 interviews were conducted. The so-called 'main caregiver' was identified within the families where the tasks associated with the care were divided among different family members who participated in providing the care. The identification of such a person was based on a simple question focused on listing all family members engaged in providing the care, followed by an estimation of the burden that the listed persons bear. Contact persons then reported an average time allocated for the care by each caregiver and frequency of visits to the senior to provide care. The person who bared the major burden (or provided care for the longest time or the most frequently) was considered as the main caregiver. If such an individual was the contact person, the interview continued. If not, then the contact person was asked to mediate contact with the main caregiver and consequently the interview was performed with this person. The sample is differentiated by region (4 caregivers come from Prague, 50 are from Bohemia, whereas the remaining 8 caregivers come from Moravia), size of settlement (7 interviews are from settlements with more than 100.000 inhabitants whereas 55 interviews are from smaller settlements) and gender (49 caregivers are females and 13 are males).

As was already mentioned above, the in-depth interviews focused on conditions under which the informal care was provided, on circumstances that determined the nature and character of the care, on motivation for providing the care and on the impact that the care had on the lives of caregivers. Respondents were also asked to identify the key barriers and obstacles they had to face during the course of caring. They were also asked to provide their reflection of the care and the way in which care was provided.

A substantial part of interviews was focused on the care as such; what actual tasks were performed by the main caregivers themselves, what tasks were performed by other caregivers, duration of the care, etc. Specific questions were asked about the bonds that caregiver had with the senior, the household (type of dwelling, number of persons within the households) and the social services used on demand or regularly (food supply, cleaning, washing, personal care, etc.). The interviews were focused on describing the stages of the care, i.e. how exactly the care started, what were the major discontinuities during the caring process, how long the care lasted, etc. Special attention was paid to the interaction of informal home care with professional social services and residential or, as the case may be, institutional care.

All interviews were tape-recorded and transcribed. Content analysis was then used to gain important knowledge from all transcriptions. The analysis was focused primarily on the identification of the needs. The research design enabled the needs to be identified even for those families that did not ask for any help, and which did not explicitly articulate any preferences or wishes associated with the care.

The number of interviews (62) can be considered sufficient. Due to the qualitative nature of the explorative studies, there is no need to anticipate the representativeness of the sample. Research findings are of a qualitative nature, i.e. they inform about needs but do not provide data on the population which would have been the aim of a quantitative research. Due to the fact that some of the needs appeared repeatedly, it is possible to conclude that the issue was thematically covered (Dinero 1999).

RESULTS

The following part of the paper starts with general overview of the caregivers' needs that were identified by the conducted study. Then, detailed attention is paid to individual clusters of needs. In this respect some clusters (specifically the clusters involving psychological, emotional, social and health needs) are described jointly because of similarities in the way each caregiver identifies the typical patterns for satisfying those needs.

OVERVIEW OF THE NEEDS

Altogether 76 different needs were identified within the conducted interviews. In accordance with objectives of this study, the needs were identified only with respect to caregivers, i.e. the needs of other stakeholders such as seniors or social workers were not included on the list. For all identified needs, the substantial gaps between current practice and the optimal situation were identified. Some of these gaps are obvious from cited excerpts from the interviews. Caregivers' needs were then grouped into nine major clusters based on the thematic similarities. The list of all needs and their affiliation with the clusters is presented in Table 1.

Needs cluster	**Needs**
Educational needs	1. information about determinants of seniors' health status 2. information about seniors' disease 3. information about possible treatments including alternative and complementary methods 4. information about available drugs 5. information about caring methods 6. information on how to exercise with seniors 7. information about diet 8. information about social service providers (contact details, how they operate, benchmarking, prices) 9. information about available financial support (care-allowance and other benefits) 10. information about eligibility criteria 11. recommendation of how to choose adequate tools 12. honest explanation from doctors concerning prospective development of seniors' health
Practical needs	13. taking care of dogs, cats and other pets 14. recruiting competent help 15. prompting relief of seniors' discomfort and pain 16. learning specific tasks (e.g. bathing, feeding and cleaning the senior) 17. transporting the senior (e.g. to/from the hospital, to the visits, etc.). 18. help with housekeeping 19. stimulation activities, senior activation 20. daily shopping 21. consulting my decisions concerning the care 22. quick and easy access to medical help or consultation (hotline) 23. involvement in the decision-making process concerning the treatment 24. rapid (emergency) help 25. operating special tools, machines, appliances
Technical needs	26. dedicated space for the senior at home 27. refitting/renovating the house/flat 28. eliminating barriers 29. moving within the flat/house 30. purchasing new equipment into the household (decubitus bed, special chairs, etc.) 31. purchasing a new/different car (capable of transporting a wheelchair) 32. rearranging the flat/house 33. house/flat repairs; maintenance of the garden
Administrative needs	34. minimising the administrative burden 35. help with legal issues 36. help with administrative issues related to the care 37. help with other administrative issues

Needs cluster	Needs
Psychological needs	38. health problems (depression, sadness) 39. health problems (nervousness, irritability, anger, stress management) 40. low self-confidence, self-esteem 41. undermining caregivers' competencies and skills 42. coping strategies 43. underestimating the negative impacts of care on the caregivers' health 44. addressing end-of-life issues 45. inadequate perception of own limits 46. fears of the senior 47. exit strategy (what to do after care giving)
Emotional needs	48. loneliness, perceived isolation 49. lack of appreciation from the senior 50. lack of appreciation from doctors and nurses 51. spiritual help 52. empathy from the nurse 53. sharing the pain
Social needs	54. loss of friends, absence of social interactions 55. focus on the care accompanied with elimination of other interests 56. detrimental family relationships 57. other interpersonal relationships issues 58. communicating with professionals (especially with medical doctors) 59. communicating with other family members 60. sharing experiences with other caregivers 61. how to restart when caregiving is over 62. caregivers' activation 63. reestablishment of social contacts 64. division of labour within the families
Health needs	65. health problems (infections and consequent separation from senior) 66. health problems (urgent surgery) 67. health problems (preventive visits — long queues; bad time-management at the doctors) 68. no time to relax
Financial needs	69. financial help compensation for direct expenses 70. subsidies for indirect costs 71. return to work 72. performing their job (employment) 73. paying for their old-age pension 74. interruption of regular payments (e.g. mortgage, life-insurance) 75. maintaining their job (as in the case of maternity leave) 76. space for caregiver when the senior must stay in a hospital

TABLE 1 Typology of identified needs

EDUCATIONAL NEEDS

Educational needs were identified by the lack of basic information about important aspects of caregiving and by incorrect answers to knowledge questions. The actual presence of the need was validated by relevance and usefulness of such information from the perspective of caregivers. Informational help to caregivers is driven by the fact that most caregivers are not nurses or social workers, but they are laymen without formal education in the field of caregiving. The following excerpts from interviews document situational factors and practical circumstances of educational needs:

> *"Everything was suddenly so new for me. I did not know anything about caring" (CG_14_1).*
>
> *"My doctor did not tell me anything about that disease. So I had to find all the information on the Internet. But you know … I am not a medical doctor, nor a nurse … so I do not understand a lot of things" (CG_15_1).*
>
> *"For me the most difficult part was the decision-making. What should I do when he has heavy breathing? Should I call an ambulance? Should I ask somebody for help?"*
>
> *"If I knew in those days that I could have somebody who could help me with feeding and bathing, I would have definitely used such help. But I had no time to search for such information" (CG_19_1).*

Once the care is provided, the usefulness of educational campaigns is low. Such campaigns should target the group of *potential* providers of care; however, caregivers do not have time for searching and retrieving general information. Moreover, educating caregivers might be a long-lasting activity with an uncertain effect. Therefore, systematic education might be useful for those who are 'in-between' providing care, e.g. they finished caring for one senior member of the family and expect to provide care to another(s).

PRACTICAL NEEDS

Practical needs require not only knowledge but also specific skills; practical needs go far beyond only knowledge. In this respect desired, informal home-care (family care) would be supported by easily available and affordable social services. Especially in rural areas, the needs of caregivers are not satisfied due to the low availability of these services. In many cases, social services are not used by caregivers because a conflict of interests between social service providers and their clients (caregivers) occurs. The fact is that social services are often provided on a contractual basis intended for regular and long-term use. However, such a requirement does not correspond with caregivers' needs that come occasionally and have an ad-hoc nature.

> *"Our general practitioner never visited my father at home. Never" (CG_12_1).*

> *"The others in my family are afraid of providing the care. They do not know how to do it, they do not want to hurt him and so ..." (CG_12_2). The other family members were too scared of the care" (CG_17_2).*

> *"One social worker that I invited showed me how to manipulate with the body, how to wash her, how to change her clothes and so on. That was extremely useful"(CG_14_2).*

> *"My father, he was quite big and heavy. So it was extremely difficult to even turn him on the bed" (CG_16_2).*

The need to develop caregivers' practical skills is driven by their low awareness about the standards of the care. Extensive and comprehensive training of caregivers would not only supply specific information but it would also help to improve the quality of informal care.

Satisfying these needs would be useful through co-work when the caregivers would perform a certain operation together (or under the supervision) of a skilled, professional social worker. Shared care (i.e. the joint effort of the family caregivers and social service professionals), co-work or mobile hospices may yield promising results. Satisfying such needs should take the form of doing certain operations together with a skilled social worker. Co-work is useful for those in the early stage of providing care. Otherwise, caregivers use the method of trial and error, which may be at the expense of quality of the care and comfort of the senior. The aim is to teach how to do the things right, especially to prevent injuries, to enable visits to the doctors, and to offer shared rooms in the hospitals (what to do with the senior if caregiver must stay in the hospital).

PSYCHOLOGICAL, EMOTIONAL, SOCIAL AND HEALTH NEEDS

Psychological and emotional needs are strongly associated with the different phases of the caregiving process. During its initial stages, it is the need to deal with the (often sudden) onset of the care, whereas during the routine caregiving (when the role of the caregiver is already established), it is especially the strategies of dealing with the burden and preventing burnout.

> *"If I could have used the psychological help, I would definitely have done it. The thing is that during the care, the relationship with my youngest daughter greatly deteriorated. I was so deeply involved in caring for my mother that the raising my child, I totally screwed it up" (CG_11_2).*

> *"What I missed was the psychological support. To hear from somebody that you are doing things right, that you are on the right track, you know ..." (CG_17_1).*

Social needs comprise especially communication skills of caregivers with professionals (such as medical doctors, nurses, social workers, etc.). It also covers communication skills when negotiating about the division of labour within the family (among family members; engaging other care providers; delegating some of the duties associated with caregiving to others). Social needs also involve gaps that come from the fact that caregivers usually interrupt their social contacts (colleagues from work, acquaintances, other relatives, etc.) because they are so deeply involved in caregiving that they do not have time for such social activities. Social needs were indicated by the declared loss of (or at least substantial reduction of) social contacts and by the amount of time devoted to caregiving.

> *"During the caregiving I was not able to invite any visitors into my home. No friends, colleagues from my previous work, nobody was allowed to enter the house where I provided care to my mother" (CG11_1).*

> *"The care totally eroded our lives. My family broke-up, I suffered the divorce, and my sister experienced the same trouble. So for now, both of us remain alone" (CG_16_3).*

Apart from the above presented outcome needs, from the narratives provided by individual caregivers, there are also typical methods how their needs were solved and/or what the caregivers did within the situation which they are in. The strategies are as follows:

a) Denial of the needs or postponing their satisfaction,
b) Rationalization (i.e. problem solving),
c) Seeking professional (remedial) help.

Psychological, emotional and social needs may be met by specialized and professional counselling. The help of experienced and specialized coaches can yield satisfactory results. Here the individual attention of the skilled professional to the caregiver is essential. These needs are very often unmet; see the coping strategies. These needs cannot be outsourced because they must be provided personally (as a labour of love). Many caregivers are exhausted (physically and mentally) from providing a whole range of operations and activities that they perform rather intuitively.

Health needs are based on issues associated with the health of the caregivers. It is important to point out in this case that caregivers are themselves of an older age — many of them are older than 50. Therefore, health concerns are not rare in this population segment.

> *"When my husband was still alive, I was OK. However, when he died, my blood-pressure went-up sharply just for no reason. And then I had to go to a hospital…" (CG_15_2).*

> *"After my father died, I collapsed and now I am on sick leave for almost a year" (CG_16_1).*

> *"When she fell down, I could not lift her up. Well, I did finally, but it was at the expense of my health" (CG_19_2).*

The goal is to prevent injuries caused by the care, to enable visits at the doctors (respite), to provide shared rooms in the hospital when it is necessary that the caregivers stay at the hospital.

FINANCIAL NEEDS

These type of needs represent the payments of the costs and expenses associated with the care. These needs are related with educational needs and some others. Financial needs are further determined by the impacts that caregiving has on the status of the caregiver on the labour market, especially in the case of leaving the labour market because of the care and a decreased old-age pension (as a consequence of leaving the labour market earlier).

> *"I used to be a hard-worker. I spent 12 or even 14 hours per day in my work and the boss was very satisfied with me. However, when I started to provide care, it was not possible any more ... so I lost the job. And now, after the care is over, I cannot get a new job — there is no job vacancy for me" (CG_11_5).*
>
> *"Having your mother at home, you are punished by the system. You have to purchase everything with your own money. If my mother would be in a hospital, she would get all the drugs, bandages, infusions, etc. for free. However, having her at home, we had to purchase all that stuff" (CG_14_2).*
>
> *"I wish I could have built a new shower enclosure but it was not affordable for me" (CG_19_3).*

A high share of caregivers is over 50 years old. It is a critical stage in life concerning their position in the labour market. It is obvious that the fear of job loss and consequent decrease in the standard of living (often permanent) is one of the key stressors among caregivers. Fear from losing a job may in some cases lead to the decision to resign from providing care and to moving the senior to a residential institution. This involves comprises the families where the main caregiver is at the same time the head of the household and has dependent children, pays the mortgage, or is in pre-retirement age with no good outlook to return to the labour market. The harmonization of work and family (caregiving) lives is therefore essential. For instance, part-time jobs, shared work-positions or flexible time schedules may be helpful in this respect. One possible instrument is a secured job position, i.e. the obligation of the employer to maintain the working place of the caregiver during the course of the care. Another measure is the possibility to retire without decreasing one's old-age benefit/pension. Moreover, there is also a need to compensate the direct costs associated with the care, i.e. the purchase of tools, equipment etc.

TECHNICAL NEEDS

The last type of needs cover the redesign of a flat or house, especially barrier-free access, the installation of special handgrips, etc. These needs also represent the need to move house (when either the senior or caregiver moves in with the other).

> *"We have rebuilt the whole bathroom, installed a new shower enclosure and bidet, purchased the special seats, put the handgrips everywhere" (CG_11_4).*

A specific type of technical needs represent the need to eliminate or at least to decrease the administrative burden.

> *"It was a never-ending story of sending new and newer pieces of evidence that my mother really is totally dependent. Then I had to undergo all day long wrangling for care allowance, repeated visits of local authorities, filling-in the same information several times into the forms and applications. And then? Then you have to wait for several months to start receiving the allowance that doesn't cover the expenses anyway" (CG_11_3).*

> *"Ok, you need the wheelchair. So, you apply for it, fill-in some papers and do this kind of stuff. And then you wait for one or two months. It was too long" (CG_13_1).*

CONCLUSIONS

The importance of the above presented typology of the caregivers' needs is at least twofold. It may help to design interventions because a specific stand-alone intervention for each need would not be effective. Such a wide portfolio of interventions could be confusing for prospective clients. However, for reasonably built clusters of needs, relevant and effective interventions may be proposed. The typology of needs thus enables us to abstract from situational context and may serve as a guide for given interventions or measures.

The clusters enable the satisfaction of the given needs to be maximised. The identification of similarities and designation of their differences enables us to focus such interventions on the merit of such needs. The needs assessment and their typology then provide the opportunity for better targeting of such needs and help to optimize the satisfaction of caregivers.

The impacts of unmet needs are especially in the a) extensive burden of the care, b) decreased quality of care, c) lower attractiveness of family care (putative burden) and d) malfunction of current interventions and policies (high non-take-up).

Further research may try to quantify the needs either in terms of their prevalence (i.e. by the means of representative cross-sectional research) or in terms of the amount of such needs. Another study may focus on proving the acceptability of the identified measures either through a case study approach (e.g. the field experiment), or by declared measures (for instance by the willingness to pay).

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