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Arpo Aromaa:

*Estimating disability occurrence, degree of limitations,
need for help and determinants of disability in national
health surveys*

Estimating disability occurrence, degree of limitations, need for help and determinants of disability in national health surveys.

Arpo Aromaa, KTL National Public Health Institute, Helsinki, Finland

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1. Introduction

Functional ability is an important determinant of people's educational and career achievements and also determines how they can manage their duties and everyday chores. Functional limitations are often due to chronic diseases and impairments and when severe result in disabilities (activity limitations) and handicaps (participation restrictions). These in turn cause dependency and need for help and care. All people should be able to lead as full lives as possible. Within their resources societies try to make this possible for disabled and handicapped persons by individual rehabilitation including aids, by improved environments, educational and occupational opportunities, enhanced prerequisites for participation, providing community help and care, and by institutional care.

The economies and services of industrialized nations today face the demands of quickly aging populations, whose needs must be met. Simultaneously, the decreasing incidence in several countries of some chronic conditions may help to alleviate the increasing burden of diseases and disabilities. Many developing countries face the threat of increasing chronic morbidity and disability. Rational health and social policy and services development needs data and information on limitations and need for help and much of it can only be obtained by monitoring population health. Cross-sectional and historical data should be complemented by forecasts.

I will first discuss goals and purposes of health surveys and against this background next turn to strategies and design features. Then, I will deal with some aspects of measurement. Finally, I will briefly describe the solution we selected for Health 2000, the Finnish national health examination survey.

2. Goals and purposes of surveys

In principle, surveys are well suited for measuring the occurrence of disabilities (functional limitations, activity limitations) and handicaps (participation restrictions) by using questionnaire methods, observations or tests or their combination.

Cross-sectional health and disability surveys often have some of the following aims:

To obtain valid data and information

- a) On prevalence, degree of severity and distribution in the whole population or the non-institutionalized population of limitations, restrictions and need for help and benefits,
- b) On degree of severity and distribution in the disabled population of limitations, restrictions and need for help and benefits, and
- c) On determinants and consequences of functional limitations and need for help.

Repeated cross-sectional surveys can also be used to obtain information on trends of limitations and their determinants (including diseases). Such information is essential for forecasting and planning purposes. However, changing environments and living habits complicate the interpretation of results especially on handicaps (participation restrictions). To measure incidence of functional limitations requires follow-up designs and also involves similar problems. Often follow-up designs are preferable when studying determinants of disability, although the impact of diseases on limitations can also be assessed in cross-sectional studies.

To reach aim b) might require less effort than aim a) since the survey would concentrate on the disabled population only. However, there is rarely a suitable sampling frame to be used to define the disabled population so that the results are not distorted.

3. Strategies, designs and implementation features

The selected strategy may either be to obtain disability data as part of a multipurpose national survey or by carrying out a separate disability focused survey in the whole population or the disabled population. Typically relevant national surveys comprise health interview and health examination surveys, level of living surveys and labor force surveys. The consequent target populations can be the whole population, the non-institutionalized population with a separate study in the institutionalized population, the working age population or the disabled population.

The survey can also be carried out in one or two stages. In the latter case the first stage of the survey would be used for identification of those to be interviewed or examined in more detail in a second or later stage. In addition to some complexity the main drawback of the two- or multi-stage survey is that non-participation to the later phases tends to increase when the number of stages increases. Also, to avoid biased findings the screening of the target group of disabled persons must have high validity.

The advantage of multipurpose national surveys is that information is simultaneously obtained on major determinants of disability, and the disadvantage that the amount of data that can be obtained on disability and need for help often is much more limited than in a special survey on disability. This drawback is smallest in health surveys. A survey of the disabled population may successfully be carried out as a second stage of a multipurpose survey although non-participation may increase. However, without an initial valid stage for case-identification the definition and source of the disabled population probably affects the findings and it may also be difficult to extrapolate from them to the whole population.

The central decision is to define the target population. For valid measurement of the burden of disability in the population the preferred samples are

- 1) Individual or household sample of the whole population or
- 2) Individual or household sample of the non-institutionalized population in combination with an individual based sample of the institutionalized population.
- 3) Another option is a population interview survey coupled with a census of the institutional population.

A further possibility of collecting more data on disability and the disabled results from opting for a two-stage design and selecting the target population for the second stage on the basis of key screening questions contained in the first phase questionnaire. The possible drawback is poor sensitivity resulting in underestimation and possible biases in the disabled group. Therefore, the two-stage approach should only be adopted after thorough assessment of the screening properties of the key questions. Many other types of samples tend to bias the findings in relation of the whole

population. This is particularly true of samples drawn from registers of beneficiaries or membership records of organizations of the disabled. Nevertheless, separate studies of these groups may be warranted in their own right.

In the context of national health surveys the basic choices are between health interviews (HIS) at home and health examinations (HES) elsewhere such as a health center. A HIS/HES combination has the advantages of both types of surveys and furthermore is very attractive to the examinees. The HIS interviewers (or nurses) can visit both the home and the institution and may achieve high participation rates. In a HIS/HES combination part or all the examinations can be carried out at home (or in the institution) and therefore it is equal to HIS in being able to reach a high proportion of the sample. Typically a HES is carried out in a health center or similar premises which require the examinees to come to the examination site.

Most often lay interviewers have experience of interviewing non-institutional persons only. They may find it difficult to approach personnel and patients in an institution. However, when researching disability it is essential that the institutional population is included in the sample and that it participates. Institution personnel may sometimes be reluctant to allow outsiders to come to talk with 'their' patients. For both these reasons it is imperative that a good training module for interviewers is included and that problems are resolved by phone or in person.

Non-participation

Non-participation or lack of information for other reasons is a great threat to the validity of any survey on disability and handicaps. The above example of the institutional population is self-explanatory since many people are in long-term institutions because they are disabled. However, often any non-participation is selective. First of all, the sickest and those with poorest functional ability may be less likely to participate both to HIS and HES. They or their relatives may feel that they are too sick to take part in a lengthy interview, their memory may be impaired or they may have impairments preventing their communication with the interviewer. In addition, the personnel in a nursing home may not allow the interview. Often, in these cases no information or very little information can be obtained. If the HES requires travel to an examination center those with disabilities may not come since it is too difficult. This problem may become smaller if taxi fares are paid for disabled persons. Another reason may be that the chronically ill do not come because they are under constant physician care. Both HIS and HES participation may be affected because some chronically ill persons, particularly those with mental, alcohol and drug problems, may not be prepared to discuss their health with an interviewer or come to be examined. It is reasonable to assume that non-participants usually are sicker and more disabled than participants.

In accordance with this, follow-up of many survey populations has indeed shown that mortality is about twice as high in non-participants than participants. The lower morbidity and mortality also holds for volunteers participating in large-scale medicine trials. We have obtained direct information about selective participation to an examination survey – FinRisk-97 senior survey – by comparing the prevalence of disability in men and women aged 65-74 who came to the examination and in those who were only later interviewed at home (Table 1). The participation rate to the examination was 75 percent and taking into account the home interview it was 87 percent. The relative risk of disability was many times higher in the HES non-participants and furthermore half of all severely disabled persons identified had not attended the examination. At least in people aged 50 and over problems of a similar magnitude may result unless participation is very high, of the order of 85 to 95 per cent. Usually it is difficult to estimate health or the degree of disability even in a remaining quite small group of non-responders except by mortality follow-up mentioned above. However, I conclude that certainly beyond age 50 or 60 most surveys underestimate the prevalence and the severity of disability in the population. An increasing non-response with time can conceivably lead to a false conclusion that the occurrence of limitations is decreasing, when it is not.

4. Methods

Surveys may rely on questions, observations and tests and, in addition, results may be supplemented from data registers and information from institutions. Questions enable the survey to capture a broad range of activities and restrictions whereas the scope of observations and tests is usually more limited. The basic problem in studies comparing occurrence and severity of disability across populations and population groups as well as longitudinally between points in time is the dependence of findings on the environmental circumstances and the changing way of life.

Interview questions

Selections of questions, some of them internationally recommended question series or scales, have been used in many surveys in North America (NCHS 1965, Wilder 1977, Canada Health Survey 1981) and in Europe (e.g. Svanborg 1977, Klaukka 1981, Martin et al 1988, Smit et al 1994, Prescott-Clarke and Primatesta 1998).

Health interview surveys typically employ variants of ADL (activities of daily living) and IADL (instrumental activities of daily living) questions, which concern both disabilities (activity limitations) and handicaps (participation restrictions). The idea is to find out what the person concerned thinks he can do and to what extent he is limited in doing so. Examples of frequently used internationally recommended question series and scales to measure disability and/or health related quality of life are the following: 1) ADL questions (Katz et al 1963), 2) OECD disability questionnaire (McWhinnie 1981), 3) EuroQol (EuroQol Group 1990), 4) SF-36 (Ware and Sherbourne 1992), and 5) the WHO recommended questions for long-term physical disability (de Bruin et al 1996). Some of the shorter series cover only a small part of the functions and activities relevant in the population. Also, they measure relatively severe limitations and restrictions. Therefore, typical prevalence figures obtained below 60 years of age are low, too low when thinking of the abundance of milder limitations. Typically, ADL and IADL questions are geared toward limitations of physical functioning. Some of the question series have been tested for validity and reliability and others have not (McDowell and Newell 1996). Future development should go the direction of covering a sufficiently broad range of functions and activities, and of devising questions and classifications describing also milder limitations. Perhaps ways can also be found to obtain measures of 'positive' functioning. Finally, it would be gratifying to know that the individual questions or combined measures derived from them are sufficiently valid and reliable when validity is defined by comparing the replies to actual ability to carry out activities and tasks. Often health professionals' estimates have been used and can be used as validity criteria and validity has been assessed in patient series with considerably high prevalence of disability (Kaufert et al 1979, Kivelä 1984, Jette et al 1986). Unfortunately, the findings of such assessments cannot be extrapolated to the performance of the questionnaires in population surveys with generally a much lower prevalence of disabilities and lesser severity. Thus, there are many reasons why currently available and recommended disability questionnaires may not perform well enough in the non-institutional population and certainly not in middle-aged and young-old populations.

Questionnaires but also the selection of observations and tests should be developed to take into account the need to capture at least one or a few items from the most important areas and types of disabilities and handicaps. Many prevalent limitations described in the WHO disability classifications (WHO 1980, 2001) could probably be covered in general terms. Part of the development work should comprise selecting one or two representative variables for each area to be described. The need for tested recommended instruments is obvious. The development effort should aim at instruments of different length and complexity. To assess their performance would mean empirical testing in both patient series and in the population. The outcome would be a selection of shorter and longer instruments with known properties and known correlations with each other and a longer standard instrument.

Functional limitations have been widely surveyed in national surveys in EU member countries. According to the ongoing EU Health Monitoring Program project on national health examinations and health interview surveys 11 of 22 current HIS contained disability items (Hupkens and Swinkels 2001). Many of these surveys used questions derived from internationally recommended instruments such as the OECD disability questionnaire (McWhinnie 1981). Of the 11 surveys 9 contained ADL items, 11 general limitations of activity, 7 long-term limitations of activity, and 7 long-term physical disabilities. In addition there were three HIS/HES studies containing tests for functional status, vision, hearing and cognitive function and two with questions and tests on functional disability/ability (Koponen and Aromaa 2001). Despite of the wealth of information in these and other sources their general usefulness and comparability is reduced by differences between the surveys both in design, in participation, and in the questions employed. EU-wide surveys (European Labour Force Survey 2002, European Community Household Panel) employ similar disability questions in all participating countries and therefore overcome many comparability problems. However, the number of disability items in them is quite limited.

Some problems are common to all interviews inquiring about what a person can do - not what he or she does. First, not all subjects have experience of all the items concerning milder limitations. For example, not all of elderly persons have tried to run or even walk for a longer distance. Old men may not be able to cook food just because they have never learned how. Interviewees have to guess how well they would manage it and the interviewer cannot observe the relevant activity. It is not surprising that the correlation between replies and observations may not be high in such cases. Second, questions on psychological performance or social functioning may often be too abstract and the replies may not have much to do with real performance. Third, often people wish to make a good impression on both the interviewer and

themselves or keep up their own self-esteem and hope. They may then easily overestimate their true abilities. Nevertheless, as noted above, studies of patients have shown that interview findings and observations by health care professionals are quite strongly correlated.

Proxy answers are essential when the person concerned is unable to communicate, has communication difficulties or is clearly unreliable. If possible the information should be obtained from a person who knows the interviewee's everyday activities and performance well enough. In an institution a proper source of information would probably be a nurse in the ward and at home a family member and/or a home help. Permission to gather and use the information must always be obtained. In our own experience we have not found it necessary to devise special questions for proxy answers but have replaced this by instructions to the interviewer. However, our interview schedules contain a separate final structured part for the interviewer's observations on ability to move about, need for help in everyday chores, vision, hearing, speaking and understanding speech.

Observation

At least some information independent of the person's answers should be obtained in all surveys of disability. Structured observation by the interviewer or examiner is the first and simplest choice. Both during interviews at home and visits to examination sites it is rather easy to observe the person's walking, sitting, reading, writing and hearing. Findings should be recorded. It would be extremely useful to be able to observe the person to carry out some everyday activities. Unfortunately time constraints often prevent this. Furthermore, to secure comparability, all persons should perform the same activities. An observer's assessments add to the information available and improve its validity. However, they cannot correct the problem of different assessments at different points in time and can do little to remedy the lack of comparability between population groups.

Tests

Tests can be and have been designed concerning the actual performance of specific everyday activities or activities at work. Unfortunately, many of such test situations are so time consuming that they cannot be built into a field survey. Instead, they could be carried out on a sub-sample to describe more clearly limitations and their degree. Many established tests that can be included in field surveys concern functions and their limitations and are often closely correlated with diseases and impairments. Examples are vision, hearing and cognitive function tests. Others may be much more complex to carry out and they are often correlated with the ability to perform some usual activities. Examples are tests of reaction time, balance, walking speed or handgrip strength. Some of the tests are simple enough to be carried out at home whereas others require a health examination setting. Many tests are rather narrow in scope and do not directly describe the person's functioning in everyday chores nor do they describe handicaps (participation restrictions). However, they have particular advantages. First, they can be carried out in a standardized manner so that results can be compared between persons, population groups and across countries. They can also be compared over time. Second, their outcome is independent of changes in the environment and way of life. Therefore, independent test results can be used to understand the findings based on other methods. Third, their results are of value in their own right giving rather accurate information about the performance of the senses and other abilities.

5. Measurement of disability in the Health 2000 survey

A national health interview and health examination survey called Health 2000 (www.ktl.fi/terveys2000) was carried out between September 2000 and June 2001 by KTL in collaboration with Statistics Finland, major Finnish research organizations and Pension Insurance organizations. A cluster sample was drawn of the whole population, altogether 8 028 persons aged 30 and over, in 80 regions (160 municipalities). An interview was carried out at home or in an institution and one – two months later a health examination was carried out by one of the five field teams. Each team comprised 16 – 18 persons (doctors, dentists and nurses). The mean duration of the interview was 90 minutes and that of the examination three to four hours. Home visits were arranged to all persons who did not attend the health examination. During the home visit many of the measurements and tests of the examination proper were carried out. Participation to the interview was over 90 percent and we expect that the participation to the health examination will be about 85 percent. In addition to cross-sectional analyses of occurrence, severity and distribution of limitations the findings will be compared with similar earlier information obtained in the national Mini-Finland Health Survey in 1978-80 (Aromaa et al. 1989).

The topics of the Health 2000 survey range from determinants of health through personal risk factors to major chronic conditions, functional limitations, disabilities (activity limitations) and handicaps (participation restriction). Use of care and medicines was also surveyed. New questions were constructed to measure need for help and care and met and unmet need. In addition to questionnaires and interviews (CAPI) information on functioning was obtained by a number of tests.

Questions on limitations of basic and usual activities were derived from variants of ADL and IADL (Katz 1963) and the OECD questionnaire (McWhinnie 1981) as employed in the earlier Mini-Finland survey (Aromaa et al 1989). Further questions were developed to better cover limitations of various functions and participation restrictions. Cognitive capacity was measured by the short MMSE and tests of short-term memory were carried out. Questions were also included on working capacity, need of aids, rehabilitation and help. Availability and use of necessary help and aids were further topics. We also inquired to what extent any chronic disease or impairment reduced the person's ability to work, to carry out tasks at home or to be active in his leisure time. In addition to the mentioned internationally used source questionnaires we included the EuroQol (EuroQol Group 1990) for international comparability and another health related quality of life instrument, the 15D questionnaire (Sintonen 1981 and 1995) for comparability with the Finnish national health interview. The choice of interview and questionnaire methods was influenced by the following considerations. Comparability to the Mini-Finland Health Survey had to be retained, sufficient international comparability must be secured, both severe and milder disabilities need to be captured, and the time and space for disability questions in the interview and the questionnaires was limited.

In the health examination proper functions were measured by the following: a vision test, a hearing test, a test of handgrip strength, a test of reaction time, tests of cognition (MMSE, short-term memory), a balance test, a test of ten joint functions, a step test, a sitting down and standing up speed test (five times), and a walking speed test were carried out.

First reports on function and disability will be published in 2002. In addition to descriptive and cross-sectional analytic data we have access to a re-examined cohort of 1000 persons originally examined in 1978-80. Therefore, the purpose of the disability part of the Health 2000 survey is to assess the occurrence of current functional limitations in Finland, to assess their severity and distribution as well as to analyze their determinants in the cross-section. It will also estimate incidence of disability and its determinants in the longitudinal cohort study. Both approaches will also be used to evaluate and select methods for future use. Finally, a comparison of the 2000-2001 data with the 1978-80 findings provides the first definitive information about the temporal development of the population's functional ability and limitations in Finland and elsewhere. We hope that these findings will enable us to make sensible forecasts of need for help and care in the near future and enable us to provide much better estimates of future need of services.

6. Conclusions

European and Finnish experiences suggest that there is still a long way to go before both designs and methods used in health and disability surveys are developed to the level they should be. In particular, it is essential that the findings can be generalized both to the whole population and to disabled people, that the strategies and designs used are of high quality and that methods used provide a sufficiently comprehensive and true picture of disability. Furthermore, methods should be developed to such an extent that the findings are known to be valid, reliable and comparable between surveys and that time trends can be estimated. Much cause for concern is due to the often relatively high and increasing non-response rates in many countries. However, there are also many promising developments and much ongoing work. One way forward is to combine questionnaire methods with observations and tests. One future aim must be to cover at least by one item many of the types and areas of disability described in both the previous (WHO 1980) and the new WHO disability classification (WHO 2001). This requires further development and research leading to thoroughly tested instruments of varying lengths to meet the demands of population surveys for valid and brief measurement methods. In the meantime thoughtful international expert recommendations can be expected to improve the coverage of the measures and to improve validity and comparability of the findings. Goal conscious research and development work combining European and worldwide experiences and expertise can be expected to lead to success. For both scientific and practical reasons such advances are urgently needed.

Table 1. Absolute need for regular help several times a week and occasionally in persons aged 65-74 years in the Finrisk –97 senior survey. 1288 men and women.

| Need for help | Field examination | | Home interview only | | Total | |
|---------------|-------------------|---|---------------------|---|-------|---|
| | N | % | N | % | N | % |

Regular need

| | | | | | | |
|--------------------------|------|------|-----|------|------|------|
| No | 1068 | 96.0 | 132 | 75.4 | 1200 | 93.2 |
| Yes | 45 | 4.0 | 43 | 24.6 | 88 | 6.8 |
| Occasional need + | | | | | | |
| No | 1017 | 91.4 | 114 | 65.1 | 1131 | 87.8 |
| Yes | 96 | 8.6 | 61 | 34.9 | 157 | 12.2 |

Absolute need for regular help several times a week: Unable to carry a shopping bag, to walk for 400 meters, to climb stairs, to do shopping or banking or almost or completely blind.

At least occasional need for help: Regular need or unable to read a newspaper, to cut toenails, to perform heavy cleaning or to use public transport.

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