

REPORT

Mental Health Service Evaluation: Developing Reliable Measures First International ENMESH conference European Network for Mental Health Service Evaluation June 10-12, 1994

Introduction

The first international conference of ENMESH was organized in the Academic Medical Centre in Amsterdam, The Netherlands. During this three day meeting about hundred participants from 21 European countries discussed important subjects related to instrument development. The conference started on Friday 10 June with a plenary session in which participants were welcomed by professor Krol, member of the Board of Directors of the Academic Medical Center.

DAY 1

In the opening session Aart Schene described the historical backgrounds of the network. This WHO collaborated network was established in 1991 by Knudsen, Schene and Thornicroft. Later Tansella and Vázquez-Barquero joined the core group. In 1994 the network had 167 members from 26 countries. Of these 93 were psychiatrists, 30 called themselves doctor and 12 were psychologists. Schene further clarified the aims of the network: to organize an European network, to promote the development and dissemination of study designs, research instruments and mental health outcome indicators and to function as a clearing house especially with regard to the Eastern European countries. Till then membership was unevenly distributed over the European countries.

The core group of the network decided to organize the first conference around four themes that the members mentioned as to be of special interest to them: Need Assessment, Quality of Life, Family or Caregiver Burden and Satisfaction with Services.

WHO and the Development of Psychiatric Instruments

Professor Sartorius first gave an overview of thirty years of WHO experience in developing instruments for psychiatric research. A lot of work has already been done as can be seen from the WHO book about all available WHO instruments considering psychopathology, functioning, handicaps, quality of life and services. There are 40 released WHO instruments and another 60 that can be consulted. Some are in computerized versions.

The instruments on psychopathology are already of high quality. They have to be updated every few years. There will be some further developments of special modules, which can be added to the psychopathology instruments. What is needed is a new classification of disabilities and impairments. Sartorius asked young researchers to be active in the development of instruments on these issues, although he mentioned that it are not the fields most people in psychiatry are interested in. At the moment WHO is developing a

Quality of Life instrument, the WHOQOL, which concentrates on the patients perception of QoL and not on the objective sides of QoL. In this field it is also important to develop measures by proxy: for children, people that cannot speak, demented people and others. Other important areas are pathways to care, quality of care, and scales for environmental circumstances.

Next Professor Sartorius mentioned four dilemmas in instrument development: (1) should we especially do studies to develop an instrument or should we try to find out a certain subject and by the way develop an instrument. He thought the second way to be more easy, because it is less difficult to get the money for that, (2) should an instrument be monocultural or multicultural, (3) should we develop these instruments on one side or many sides (unicenter or multicenter), and (4) should we work on instruments that are used once or twice or for a very long time in different studies.

At the moment there are no instruments to measure (1) stigma and intolerance, (2) burn out for patients, normal people and carers, (3) communities capacities to accept more troubled patients: how much can a community take before it starts to reject, and (4) what values are communities giving to mental health: mostly it is low, so how can we raise it? He suggested that standardized assessments of psychopathology would exist by 1995, disability and handicap instruments by 1998, needs assessments by 2002, and all these tools would be integrated by 2005. Lastly he mentioned that there are a lot of great differences between countries. Countries can only collaborate if people in both types of countries agree on the problem. The collaboration should not harm the sides and there should be an equal sharing of tasks. Ethical rules are important.

Graham Dunn gave an excellent paper on the technical aspects of instrument development. He concentrated on the complicated relationship between reliability and validity of instruments, and gave examples from the field of needs assessment.

In the next session four speakers introduced the four themes of the conference.

Needs Assessment

Graham Thornicroft start the theme of Needs Assessment. Needs are becoming important for service provision in certain countries. Budgets more and more are following the measurement of needs. A need is something that is not had, is required and essential. Conceptualizations of needs are quite difficult. What are needs? It can be defined as a deficit in health functioning. Or there is a need when there is a deficit and there is an effective remedy. Or there is a relation with desired outcome. Needs are often defined by professionals. Demands are expressed wants by service users. He defined needs as a stage of reduced or abnormal mental/social function associated with a psychiatric disorder which asks for professional intervention by a third party, a professional.

Quality of Life

Peter Huxley gave an introduction on Quality of Life. He clarified the different views on quality of life and also the very different perspectives people are using when they talk about quality. There may be an important difference in using QoL measurements in clinical practice and in research. QoL is being used by politicians but Huxley found it also to be very useful in clinical practice. Can people be maintained in the community, that is the most important question to be answered.

Huxley tested different QoL models: Lehman, Bigelow, Frankling etc. By using path analysis it was shown that only the Lehman model had some empirical basis: the personal characteristics influencing objective QoL indicators; objective QoL indicators influencing subjective QoL indicators; and objective QoL indicators and subjective QoL indicators both influenced global well being. There was no influence of personal characteristics on subjective QoL indicators nor on well being. The measurement of quality of life is sensitive for psychopathology. It can be used as an assessment of the different places people and patients are living in.

Family or Care-Giver Burden

Aart Schene gave an introduction on Family or Caregiver Burden. First he gave an historical overview of the family burden research. In this overview he made clear that there has been a gradual shift from thinking in terms of burden to thinking in terms of caregiving. That means that recently also the more positive aspects of having a psychiatric ill family member are investigated. Researchers are looking more on the tasks caregivers have to perform, and to understand caregiving they are using stress-coping-appraisal models.

Next the results of a recent review of all burden/caregiving instruments available in English was given. Schene together with Tessler had send a questionnaire to all researchers active in that field. They found 21 instruments, which showed great differences in terms of method, items, and psychometrics. Factor analysis conducted on data collected with these instruments have made the concept of caregiving more clear.

Patient Satisfaction

Because of illness, Mirella Ruggieri was unable to attend the conference and so at short notice Michael Phelan introduced the fourth theme, patient satisfaction with services. Why should we measure satisfaction? In the long run there must be a relationship between the quality of the care and the satisfaction. May be not in the short term. But it is important that people are satisfied with their services, otherwise there is a possibility that there compliance is low. Satisfaction must have an influence on continuity of care. For most of the long term patients the care system is an important part of their life. As with most of us it is our job that makes life satisfaction. For our patients the mental health care system has an important task in that respect. If patients are satisfied with the care they receive this certainly must have a great influence on their quality of life.

Variables that determine satisfaction are the personality of the patient, their expectations (low expectations gives high satisfaction) and the quality of care. Of course there are a lot of difficulties in measuring satisfaction: the amount of contact between patients and services, the multidimensionality of the concept, the impact of giving your opinion about satisfaction on staff etc.

Mental Health Economics

Although not a formal theme of the conference, mental health economics is a vital element of mental health service evaluation, and Martin Knapp closed the first afternoon with a paper on health economics research. There is a complex relation between budgets, resources, services and outcome. There is a growing scarcity of budgets and resources because expectations are rising, populations become older, budgets go down (for instance

for political reason) and people have higher standards of care. So we have to be more careful in allocating our budgets. That means that there exists demands for health economics perspectives: accountability, audit, central policy, product development, development of new drugs (some countries already expect cost-effectiveness studies for new drugs to be registered). Apart from these arguments there exists also a pure research interest for doing health economics research.

There are different types of outcome studies: cost-effectiveness (welfare), cost-benefit (monetary outcome) and cost-utilities analyses (single indicator: quality adjusted life years). Both last methods have till now not been successfully used in mental health. Knapp ended with the suggestion that there should be more health economists in EnMESH.

DAY 2

The second day of the conference was organized in parallel workshops on the four themes. In these workshops participants gave papers on their own research activities. The morning sessions concentrated on conceptualization and assessment. The afternoon sessions on clinical application. At the end of the day a plenary session was organized in which results of the workshops were summarized by four reporters.

The **need assessment workshop** concentrated on the value judgement of needs. Needs assessment is in part a clear concept. The more basic needs are clear, but the higher ones are more difficult and here opinions are quite different between different groups. For instance users, staff, politicians and tax-payers can have quite different views on this. Studies showed that the concept is clinically relevant. Different instruments are available now, but their psychometrics need further study and these instruments have to be studied together. A special difficulty is the measurement of the so called not meetable needs. Participants also mentioned that the overlap between Quality of Life, Needs Assessment and Satisfaction with Services should be studied in more detail.

The **quality of life workshop** also highlighted the overlap between Needs Assessment and Quality of Life. Interesting papers on the conceptualization were presented. In one of these a method called concept mapping gave much clarity about the different domains of the concept. Also the method used by WHO for the WHOQOL has offered much information about the concept. Quality of Life turned out to be a good concept to bridge between social services and psychiatry. Of course there are quite different views on a patient's quality of life. By proxy measurement are necessary. It can be used very good in clinical practice.

The **satisfaction workshop** also made clear what kind of methodological problems there exist in the measurement of a complex multidimensional construct such as satisfaction. There is a lack of theories, few standardized methods, too much positive satisfaction, lack of correspondence between what clients see as satisfaction and what researchers. Other methodological problems have to do with the Hawthorne effect and with the frequency of measurements. Non-responders is a big problem: can we follow them up by different methods. Satisfaction should be part of a set of outcome variables. People's condition can improve, but their satisfaction can go down. Participants concluded that it will take a long time before we have standards.

The **family/caregiving workshop** concluded that empirical studies during the last decade have made the concept more clear. With regard to validity participants concluded that it is clear that we are measuring something, but its more difficult to theorize about the concept. The word burden should be dropped and what should be included in the assessments are the possitive aspects. The psychometrics of most instruments are not very well established. It is also clear that the concept is clinically relevant. Patients have an impact on their relatives. Relatives are very keen to talk about these problems. But what do patients think about it. Especially if we use the word burden. The consequences of caregiving cannot be measured in a normal population, although many normal families can be quite stessful to live in too. Sensitivity for change is a difficult subject if we do not have valid instruments.

The discussion at the end of this second day made clear that the four themes show quite some overlap. They shoud be studied in interaction, and studies should also use other measures, so that we can validate and learn more about the relationship with other more clear concepts (by factor analysis, cluster analysis etc).

All four themes are of great importance for psychiatry to day, and all four are being studied more from a practical background than from a theoretical. However the theoretical basis should be clarified, and for that we have to study and use theory and researchers from other fields as philosophy, sociology, economics etc. Doctors and psychologists are empirical driven: we need more contact with other groups, learn from them, talk with them and use their theories.

DAY 3

The third day of the conference tried to link the discussions about the state of the art with ideas about the future. Four discussants presented their ideas.

Durk Wiersma talked about **need assessment**. There are two instruments of importance; the CAN and the MRC Needs for Care Assessment. The use of these instruments transculturally is difficult, because mostly the populations are quite different. Important is the relationship between unmet and met needs. Also important is the percentage of patients not in care and the percentage having unmeetable needs. From the studies done so far it is difficult to evaluate mental health care. Both instruments should be used in one study so that we can learn more about validity. The methodology of need assessment is complex because it combines the assessment of quite different things: problems, interventions and the interrelatedness. Especially the interventions need further standardization. Another point is that researchers have to present their data in such a way that policy makers and clinicians think that they are usable. A good method for that is stil lacking. We should use these need assessment instruments together with other instruments, for instance satisfaction instruments: professional satisfaction, caregiver satisfaction and patients satisfaction and social functioning. Hopefully ENMESH can help to organize such a study, and help with the development of a common used instrument that can be translated into a lot of different languages.

Tom Burns gave his ideas about **quality of life**. There are at the moment 11 instruments for QoL. Seven domains are at least in 50% of these instruments. We see that the content of the instruments develops over time and there is more and more agreement about the domains: health, accomodation, leisure, occupation, support, finances, education etc.

Burns mentioned the following research priorities:

1. to investigate if the subjective and objective components of QoL scales are better measures when analysed separately or together. This could be approached using longitudinal studies with the patients as their own controls.
2. overlap with other concepts: we should use large data sets to investigate if the objective components of QoL scales and the corresponding areas of Need Assessments are measuring the same variables. Is there a common core of Standard of Living items which are being measured twice?
3. there are no gold standards, no normal value, but we should define minimum standards. If many of the objective measures in QoL scales are standard of living items, than attempts to compare them against national census data should be explored. This is of importance in cataloguing the relative poverty and disadvantage experienced by the severely mentally ill in the community.
4. theoretical sophistications: there is an overwhelming need for extensive and long term work devoted to developing a viable theoretical framework for the concept. For this increased co-operation between clinicians and social scientists is needed.

George Szmukler discussed **family or caregiver burden**. Burden is too restrictive a term, it is value-laden, pejorative to patients and omits positive aspects of caring. Caregiving is far more attractive. How do we know how the situation should be in a family if there was no patient. Should they have more money, more friends etc. Maybe it is yes, but we do not know. How is it possible to measure such disruption? There are family members who think that their life has changed in the positive direction because of having a mentally ill family member.

One does not find the term burden in chronic non mental diseases: so it is strange that we find this term only in psychiatry. Measures of caregiving may have a range of purposes; to describe the experience, to test theories, to define targets for intervention, to evaluate the effectiveness of intervention programmes and as an outcome measure in service evaluation. To understand caregiving one can use stress-appraisal-coping models. If coping is important, than interventions on coping should have influence on caregiving distress. We should not pathologize the distress of caregivers. Aspects that are also important are loss, stigma, positive aspects (personal growth, new relationship with the sick person). Most studies have a high response rate which indicates that family members are eager to let us know about their experiences. We can compare different diagnostic groups, to learn about where to put our money in, but also to learn more about other groups. ENMESH can help to get rid of the term burden. Secondly there are at least two promising instruments using different concepts (the one of Schene and of Szmukler). These should be used together in one study, to get more clarity with regard to the concept.

Michele Tansella discussed **satisfaction with services**. We know that satisfaction is a result of different variables: expectations, illness behaviour, care system (structure and outcome), self esteem, previous experiences. Satisfaction can be a dependent and an independent variable. Mostly the opinion of patients are stable over time.

Plans for future research:

1. to encourage the use of well validated and tested instruments with setting specific items and general items (so with a mixture of items)
2. to test the content validity in specific types of psychiatric services, not only for instance inpatient and outpatient, but also considering the whole structure of the service in a certain area.
3. to clarify the correlation with other outcome measures: satisfaction is not a substitute for other measures (psychopathology, functioning etc)
4. to control for bias from other factors
5. to define the dimensions of satisfaction from different perspectives (so not only multidimensional but also multi-axial: patients, caregivers, professionals)
6. completion of high standard studies: with high response rate. Also epidemiological data: representation.

After these papers José Sampaio Faria, regional officer of WHO presented his ideas about international collaboration. All member states agreed on a pan-European health policy in 1984 and again in 1991. This also included paragraphs on mental health: reduction in the prevalence of mental disorders, improvement in the quality of life of people with these disorders, and reduction in the suicide rate. The challenge is cost containment, increase in quality of care and quality of life, and further dehospitalization. This first EnMESH conference is perfectly in accordance with these aims.

He concentrated on the problems in the Eastern European countries: severe shortage of resources and few staff. For that reason we do not want to decrease the number of beds there. First we need better hospitals, and evaluation research should concentrate on the quality in these hospitals. When things should be developed in those countries this is only possible with foreign resources. What are these countries asking? To formulate policies for the future, formulate targets, formulate evaluation systems, consultation about evaluation methods, post graduate training for mental health professionals.

To prepare and disseminate evaluative research data to policy makers. How can we let them know what are the research results from well done studies in mental health services. WHO started a WHO databank on evaluative research on community based services. There is an instrument that extracts the relevant data for policymakers. Now this database is set up in three countries: these data are translated and brought available for the local people.

Dr. Sampaio Faria hoped that members of the network can help in a consultation task. WHO hopes to improve these possibilities in the future. Because it is very important that researchers in the European countries know each other, that they exchange information, and that they especially make their results available to the Eastern European countries and to policy makers Europeanwide, WHO in Copenhagen strongly supports the ENMESH network.

Next Dik van Waarden gave an extensive overview of the possibilities with regard to EC funding.

The conference was closed with a general summary by José-Luis Vázquez Barquero. He concluded that there exists a lack of theory and conceptualization with regard to the four themes. That of course has consequences for the instruments we are using. That means that we have to improve our theories. But it is not a one way process; developing instruments can very much help us to clarify the concepts. The four themes are overlapping, they are not quite distinct. This of course has consequences for the conceptualizations and the instrument development. We should combine the different themes or instruments in studies. Then we can further use the empirical data to clarify the concepts. These are new areas for discussion. They are closely connected with fields as sociology and anthropology, and one conclusion is that we are working too much in isolation from other scientific fields. We have to extend our contacts or we have to open our network for other related sciences, we should also promote collaboration. We can set up sub-groups of experts that should further develop these themes.

We should improve our designs and we should try to simplify our instruments, so that these instruments can be used by clinicians in different fields. The instruments should be applicable at different sides, in different countries. We should try to establish standards with regard to instruments.

Finally Helle Charlotte Knudsen gave a look into the future. The conference has made clear that we need smaller networks within the bigger network of EnMESH. We need a second conference within the next two years. There have been suggestions with regard to themes: quality of care, health economics, mental health utilization instruments. We should have more ideas and initiatives about how to organize and finance collaborative research in Europe. We should also work on the clearing house function.

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