Measuring Participation and Quality of Life Among Adolescents and Adults With Disabilities

Måling af deltagelse og livskvalitet blandt unge og voksne med handicap

Louise Norman Jespersen
Contents

Introduction ......................................................................................................................... 3

Aim ........................................................................................................................................ 5

Method ................................................................................................................................. 6
  Sub-project 1: Design of DanPart Questionnaire ......................................................... 6
  Sub-project 2: Psychometrics of DanPart questionnaire .............................................. 7

Ethical Considerations: ................................................................................................. 7

Publications ....................................................................................................................... 8

Perspective ......................................................................................................................... 8

References ......................................................................................................................... 9
Introduction
A standardized common language in the field of disability is beneficial to people with disabilities regardless of their diagnosis or functional limitations. When used by the individual, their family and involved professionals it brings the disability and the consequences of the disability into focus. It is also supportive for treatment, training, the fulfillment of needs, for participation in social activities, and for greater society as a whole.

A standardized language would be supported by a sophisticated survey instrument, which investigates both participation in life and quality of life regardless of diagnostic group. It is also a useful tool for the comparison of people with and without disabilities. The survey instrument should be sufficiently sensitive to changes over time to detect the effects of interventions. It is my goal to contribute to the development of such a survey instrument, which can provide valid data about participation and quality of life. The survey instrument should be easy to use in daily practice and be flexible across various diagnoses and severity of disabilities.

International Classification of Functioning, Disability and Health
There is a growing international consensus concerning the need for a standardized language. Further, that the conceptual basis for this language should be the ICF (International Classification of Functioning, Disability and Health for adults (15)) and the ICF version ICF-CY for children and adolescents.

The ICF is a conceptual framework which can be used to organize information on human functioning and its restrictions. The ICF domains are described from the perspective of the body, the individual and society in four components: body, activities and participation, environmental factors, and personal factors (15).

The focus in this PhD study is on participation, (20) and quality of life (7, 29).

Participation
The ICF defines both a positive and a negative aspect of participation. Participation is the positive aspect, whereas activity limitation or participation restriction is the negative aspect. To improve participation it is important to identify the limitations and restrictions that keep an individual or a group from participating in common daily activities. The ICF cites the gap between what an individual does perform and what the individual (in a standardized environment) can perform, as a useful guide to what can be done to improve participation. The ICF lists the following participation domains: Learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, and social and civic life.

Quality of Life
As a supplement to participation we intend to measure quality of life. Participation tells us what people do, whereas quality of life tells us what people feel. Those measurements supplement each other, since both are important in the definition of a good life.

The ICF does not address quality of life. Quality of life is defined by WHO (World Health Organization) as the subjective assessment of the life of the individual. Eight core domains of quality of life have been identified (24): Physical wellbeing, emotional wellbeing, social inclusion, material wellbeing, interpersonal relations, personal development, self-determination, and rights.
**Determinants**

The determinants this PhD study will focus on are based on the following three ICF components: *body function, environment, and personal factors*. To measure these we will use known and validated items.

**Body functioning** (with and without assistive devices or personal assistance) is the physiological functions of body systems. This includes dysfunctions and impairment, both physiological and mental. The level of functioning may affect participation and quality of life.

**Environmental factors** are considered as facilitating or hindering components in the physical, social and attitudinal environment. Examples of facilitators in the three environments are: Wheelchair access ramps, peer support and public accept. Examples of hindering components are: no access to public transportation, bullying, and prejudice.

**Personal factors** are mentioned but are not specifically classified in ICF. They may be associated with the disability (and to participation and quality of life), but they are not part of the health condition. Examples include: gender and social backgrounds.

**Terms**

A standardized language and a good survey instrument require a clear and precise use of terms, which is challenging in a field characterized by poorly defined concepts (29). The main terms used in this PhD study are defined in the textbox below.

**Participation** is the involvement in a life situation e.g. work, education, spare time activities and family life. Both objective (e.g. how many hours spent on exercise) and subjective (e.g. if a person is participating in whatever he/she wants) aspects of participation can be measured. Additional activities, such as cooking, exercising etc. are included in participation.

**Quality of life** is the subjective assessment of life. E.g. joy, vitality, anxiety and sadness.

**Existing Instruments Measuring Participation and Quality of Life**

More than 30 instruments measuring activity and participation among people with disabilities have been published (20, 27) along with a vast number of methods measuring function and health (1, 2).

Many of these survey instruments are frequently used and tested for reliability and validity on various and often selected populations with specific disabilities. There is, however, no consensus on the usage of the instruments (29). Most measures are narrow and lack a broad public health perspective which can help identify intervention possibilities.

Some of the measurement instruments are based on the ICF-model, while others are based on older models for loss of functioning. Some instruments are very narrow, measuring only participation, while others offer broad descriptions of the health and the quality of life of people with disabilities. Some instruments are global (include more than one measure), while others focus on specific domains. Some are generic (suitable for people with disabilities as well as for people without disabilities), while others focus on a specific disability. Some instruments measure objective aspects of participation, while others measure the subjective aspects. A few measurement instruments measure a combination of subjective and objective aspects.

The subjective measurement instruments can be linked to the WHO definition of quality of life. Only a few instruments which strictly follow the WHO definition of quality of life have been developed (6). Some measurement instruments are suitable for describing an individual while others provide an overview of population groups. Only a few are suitable for measuring the effects of an intervention on increased participation (1, 16, 27). Finally only a handful of instruments are suitable for describing the environmental conditions which
hinder or facilitate participation when having a disability (7, 10, 17-19, 22).

There is a need for a new instrument that is short, convenient to use and useful in clinical settings as well as for background populations. The instrument should take a public health approach, focusing on determinants of participation and quality of life in people with disabilities. The instrument should be capable of both measuring objective and subjective aspects of participation and of capturing the important elements pertaining to quality of life. The instrument should have good psychometric properties and be sensitive, in order to measure changes over time. Finally, to enable comparison, the instrument should be suitable for people with different types of disabilities as well as for people without disabilities.

**Aim**

By combining well-functioning elements from known instruments¹ this PhD study aims to develop a relatively short questionnaire with the preliminary name; DanPart. To support the use of the questionnaire we will develop an instruction manual.

The instrument will:

1. Measure participation, quality of life and determinants.
2. Have valid subscales of participation and quality of life.
3. Be specifically useful for the Danish public health sector including municipalities and health professionals.
4. Emerge in two versions. One for adolescents (10-19 years old) and one for adults (20-40 years old).

To fulfill this aim, two sub-projects have been designed.

---

¹ e.g. CHART (27), IPA (3), KAP (30), PM-PAC (12), QYPP (31), LIFE-H (9, 20) and Disabkids/Kidscreen (11, 22), WHOQOL (29), YAQOL (5), SF-36 (25) and Nottingham Health Profile (13)
Method

Sub-project 1: Design of DanPart Questionnaire

The aim of sub-project 1 is to develop a questionnaire, based on existing measurement instruments and focus group interviews including people with and without disabilities. We will design two versions of the questionnaire to meet the different needs of adolescents and adults.

Material and Methods

The intention is to recruit 13 groups of panel participants. The overall age range is 10-19 years for adolescents and 20-40 years for adults. A panel group will consist of 5 participants and will be recruited from patient associations, hospitals, residential settings, and via the social site, Facebook®.

The intention is to establish focus groups that are homogenous in age and heterogeneous in type and severity of disability. Types of disabilities will cover: Motor, sensory, communicative, psychosocial, intellectual, and multiple disabilities. Participants with very severe disabilities will be included in two separate groups. A group with severe physical disabilities and a group with severe intellectual disabilities. The participants in the group of severe intellectual disabilities will be represented in the focus group discussion and in the questionnaire by a proxy respondent (e.g. parent or carer).

To further discuss the classification of the panel group and the age-range within each group, we collaborate with The National Centre of Knowledge on Disabilities and Social Psychiatry.

All panel group participants will be collaborators in the development of the new instrument. The participants will receive an invitation with information about the project by mail or e-mail.

We will carry out initial focus group discussions (13) with the panel participants to identify any relevant areas to be included in the questionnaires. These areas will be guided by the participation domains and quality of life domains mentioned in the introduction. The data will then be analyzed via the first phase in Grounded Theory Analysis (25). Following the aforementioned stages, a first version of the questionnaire will be constructed.

The panel participants will complete the questionnaire before a second meeting. The questionnaire will be discussed, any relevant input will be used to revise the instrument, and face validity will be evaluated. The developmental process is illustrated in 1.

Figure 1: Development of questionnaire.
Sub-project 2: Psychometrics of DanPart questionnaire
The aim of sub-project 2 is to analyze the psychometric properties of the questionnaire measuring participation and quality of life in a population study of adults and adolescents with varying types of disabilities.

Material and Methods

We intend to carry out a pilot study (n = 300), in order to test the new instrument on a larger population with varying types and severity of disabilities. The pilot study participants will be chosen to represent the population to which the questionnaire is intended, and will be recruited through patient associations, hospitals, residential settings and, Facebook®. Our intention is to include all extremes: Men and women, all severities of disability and all ages in the age range, to make sure we get diverse feedback. Pilot study participants will be able to comment on the questionnaire. Additionally the participants will be asked to include the approximate length of time it takes to complete the questionnaire.

As illustrated in figure 2 the participants will complete the same questionnaire twice. This is to enable test-retest calculations.

![Psychometric analysis](image)

300 participants complete the questionnaire.

2 weeks later

The same 300 participants complete the questionnaire.

Psychometric analysis

**Figure 2: Pilot study work flow**

We intend to perform Kappa statistics and correlation analysis in order to examine the test-retest reliability of the entire study population and of the different panel group categories. Construct validity will be examined in four ways (11):

- Correlation analysis in order to examine patterns in correlations between items.
- Confirmatory factor analysis in order to examine if the data fits the model constructed.
- Local dependence (LD) in order to examine if items are too correlated.
- Differential item function (DIF) in order to examine if items function equally across subgroups e.g. men and women.

LD and DIF are key criterion for validation according to item-response theory.

We will further examine whether reliability varies by age group, by type of disability and by severity of disability. Internal consistency will be measured by Chronbach’s Alpha.

**Ethical Considerations:**

Recruitment of participants requires approval from the Danish Data Protection Agency and from the National committee for Health Research Ethics. We will provide full oral and written information about the project. We
will ask the participants to give informed consent and stress that they will be given complete anonymity. All the identities will be blurred before publishing.

Publications
The results of this PhD study will be published three ways:

1. A questionnaire and a manual.
2. A web page, which will allow panel group participants to view each version of the questionnaire and follow the developmental work.
3. A PhD thesis which will include the following three papers:

   Paper I: A combined questionnaire for measurement of participation and quality of life among people with disabilities: Theoretical basis, focus groups and face validity.

   Paper II: Psychometric properties of the DanPart questionnaire for measurement of participation


Perspective
The measurement instrument designed and developed for this PhD study will be valuable and useful to everyone interested in participation and quality of life in adolescents or adults with a disability in a Danish setting. The questionnaire has the potential to be used in residential settings to pinpoint which aspects of the residents’ lives (as a group) show a high level of participation and quality of life. Conversely, it can also reveal which areas are in need of an intervention in order to improve the participation or quality of life among the residents.

By using a population-based survey, associations between participation, quality of life and determinants can be properly studied. Societal and environmental facilitators and barriers can be identified and can consequently provide guidelines for interventions addressing specific determinants or targeting specific groups.
References


