The development of an online neuropsychological test battery

The Amsterdam Cognition Scan

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Chapter 1

General Introduction

People have been interested in the relation between body, mind, and behavior since early history (e.g. Hippocrates (460–370 BC)). The specific interest in brain-behavior relationships is currently known as "neuropsychology". When in the first half of the 20th century, in many parts of the world, soldiers were returning from war with brain damage and behavioral disturbances, the need arose to understand these phenomena and provide help. A new applied science developed, focusing on the relationship between brain *dysfunction* and behavior: "clinical neuropsychology". Clinical neuropsychological research and practice mainly relies on knowledge about human cognition (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). This is because cognitive problems accompany almost all forms of brain dysfunction and are likely noticed by behavioral expression.

But what is cognition? Paradoxically, as a neuropsychologist, I always found it difficult to grasp its full meaning. Definitions found throughout the web and in professional literature indicate how broad the concept is. According to the Oxford dictionary "cognition" is: 'the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses'(www.oxforddictionaries.com; retrieved 2016-02-04). Lezak and colleagues (2004) describe cognition as '[…] a group of mental processes that include attention, memory, producing and understanding language, solving problems, and making decisions'. To illustrate its meaning and importance for understanding brain-behavior relationships, I will give an example of what could happen if a person develops cognitive problems:

> *Sara (28) finds out that she has breast cancer at an early stage of the disease and is successfully treated with surgery and chemotherapy. After physically recovering, Sara is looking forward to return to her job as an elementary school teacher. However, once back at work, she is confronted with concentration difficulties. Things around her seem to go too fast. Sara finds it hard to keep track of everything that is going on in the classroom, and struggles when doing more than one thing at a time. She becomes fatigued and forgetful and develops severe headaches while at work. At home she is easily distracted and more irritable than she used to be. When unfairly losing her temper with one of her pupils, she feels frustrated and decides to consult her GP who refers her to a neuropsychologist.*

As illustrated in this example, the processes that are part of human cognition are crucial for how we live and experience our daily lives. The extent of cognitive problems varies largely depending on the type of brain dysfunction (e.g. extent, location, duration) and a person's individual characteristics (e.g. age, education, social setting). But even when cognitive problems are relatively mild, they can negatively affect interpersonal relationships, leisure activities, education, and professional reintegration (Schagen et al., 2014).

So, overall, cognition (1) plays an important role in the brain-behavior relationship, (2) is expressed by behavior, and (3) profoundly affects our wellbeing. This makes that measuring cognitive functioning is an important aspect of clinical neuropsychological practices. More specifically, information on cognitive functioning can be used for diagnosis, to track development over time,

to identify treatment needs, to study specific disorders, and to evaluate (new) treatments.

Cognitive assessment – Neuropsychological testing throughout the years

Neuropsychological testing is the main method used to measure cognitive functioning (Gates & Kochan, 2015; Lezak et al., 2004; Wefel, Vardy, Ahles, & Schagen, 2011). When in the early 20th century neuropsychological assessments were developed to screen recruits for the military, the required techniques and tools were adopted from intelligence and educational testing (e.g. the Progressive Matrices test; Raven, 1938). These fields also provided knowledge about obtaining reliable measurements, standardization, and the development of normative data, allowing for the development of numerous standardized neuropsychological tests. As different cognitive functions work closely together to produce human behavior, neuropsychological assessments usually consist of batteries of tests covering multiple cognitive domains.

Most neuropsychological tests are conducted with paper and pencil and require face-to-face instructions (see Figure 1). Generally, a neuropsychologist sits with the test taker and provides her or him with instructions and materials to perform a cognitive task. For example, to measure visual search skills and (motor) speed, a test leader could present the test taker with the numbers 1 to 25 printed semi-randomly on a piece of paper and ask to use a pencil to connect these numbers in increasing order, as fast as possible (see Figure 2).

Figure 1. Example of a traditional (face-to-face) neuropsychological assessment.

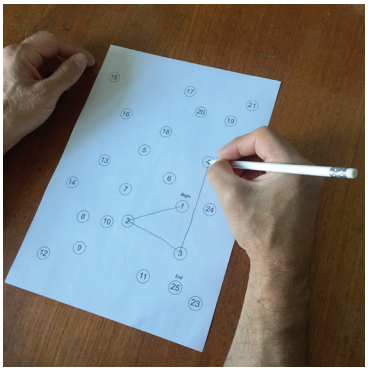

Figure 2. The Trail Making Test (part A).

In contrast to many other fields of practice, in clinical neuropsychology the use of technology is not commonplace (Kane & Parsons, 2017). While nowadays most people in the Western world have access to a computer or tablet and most children learn to use computers from an early age, neuropsychological assessments still depend predominantly on paper and pencil testing. Recently, however, computerized testing is being increasingly applied, especially in the context of larger-scale research. The main reasons to use computerized assessments in such a context are the increased standardization and efficiency in use (Bauer et al., 2012).

Neuropsychological testing in oncology

This thesis originates from the oncology field; cognitive researchers studying the association between cancer and cognition were in need of large-scale cognitive data from cancer patients. Many cancer patients develop cognitive problems during the course of their disease (Schagen et al., 2014). Cognitive decline often occurs in conjunction with cancer in the central nervous system (CNS), and possible associations with treatment for CNS tumors has long been recognized (Ahles & Root, 2012). In addition, over the past few decades it has become evident that patients with cancer outside of the CNS can develop cognitive impairment as well. This follows from studies performed on cognitive functioning following chemotherapy, endocrine therapy, and molecularly targeted agents (e.g. immunotherapy) (Schagen et al., 2014). The subset of non-CNS patients who develop cognitive impairment most commonly experiences varying, but relatively mild problems with attention and concentration, processing speed, and memory and learning (Asher & Myers, 2015). Furthermore, it has been found that these problems can persist many years after completion of treatment (de Ruiter et al., 2011; Iyer, Balsamo, Bracken, & Kadan-Lottick, 2015; Koppelmans et al., 2012).

With the growing number of long-term cancer survivors and the increasingly chronic nature of many common cancers, understanding cognitive changes and the impact on survivors' functioning is critical (Ahles & Root, 2012; Janelsins, Kesler, Ahles, & Morrow, 2014). However, currently, there are still many unanswered questions about incidence rates, risk factors, and underlying mechanisms and long-term trajectory of the development of cognitive impairment. Answering such important questions requires rigorously studying cognitive functioning in large patient samples (Schagen et al., 2014). Since it is challenging and very costly to obtain such large data sets using traditional (face-to-face) neuropsychological testing alone, there is a need for more efficient research tools to assess cognitive functioning in the oncology setting.

Online cognition – times are changing?

Online tests allow participants to complete assessments from home, without supervision, and are, therefore, potentially more time-efficient, user-friendly, and cost-efficient than traditional tests (Caine, Mehta, Laack, & Gondi, 2012). Combining the advantages of computerized testing (e.g., standardization and precision) with the advantages of online self-administration, online testing could be an important step forward for cognitive oncology research. However, thus far, there are only a few online tools available that are suitable for testing in an unmonitored setting, that are sensitive for detecting subtle changes, and that have adequate psychometric properties (e.g. test-retest reliability) and accompanying norm data. Moreover, the few tests that possess these characteristics tend to focus on memory in the context of (ab)normal aging instead of a broader range of cognitive functions.

Aim of this thesis

With this thesis I aim to contribute to the facilitation of large-scale assessment of cognitive functioning to advance our understanding of cognitive decline in cancer patients. More specifically, the aims of the studies described in this thesis are to (1) develop and (2) evaluate a research tool for self-administered cognitive assessments. In a collaboration between the Netherlands Cancer Institute (expertise in oncology and clinical neuropsychology), the University of Amsterdam (online neuropsychological testing), and the Vrije Universiteit Amsterdam (communication science), we worked with NeuroTask B.V. (web programming; https://www.neurotask.com/) to develop the Amsterdam Cognition Scan (ACS; see Figure 3 for logo), an online neuropsychological test battery intended to:

Figure 3. Logo of the Amsterdam Cognition Scan.

- Be self-administrative, developed for assessments in unmonitored settings
- Cover a broad range of cognitive functions, including the following cognitive domains: attention, information processing speed, learning and memory, executive functioning, and psychomotor speed
- Include online tests based on well-established traditional neuropsychological tests; measuring the same cognitive constructs as much as possible
- Be relatively independent of computer familiarity, language abilities, and motor abilities
- Be suitable to run on all major internet browsers and all common operating systems
- Serve an international audience (be relatively language-independent)

Furthermore, we aim to provide:

- Information on psychometric properties: test-retest reliability and validity
- Normative data

Outline of this thesis

The steps for completing development and evaluation of the ACS are illustrated in Figure 4 and described in the following chapters of this thesis.

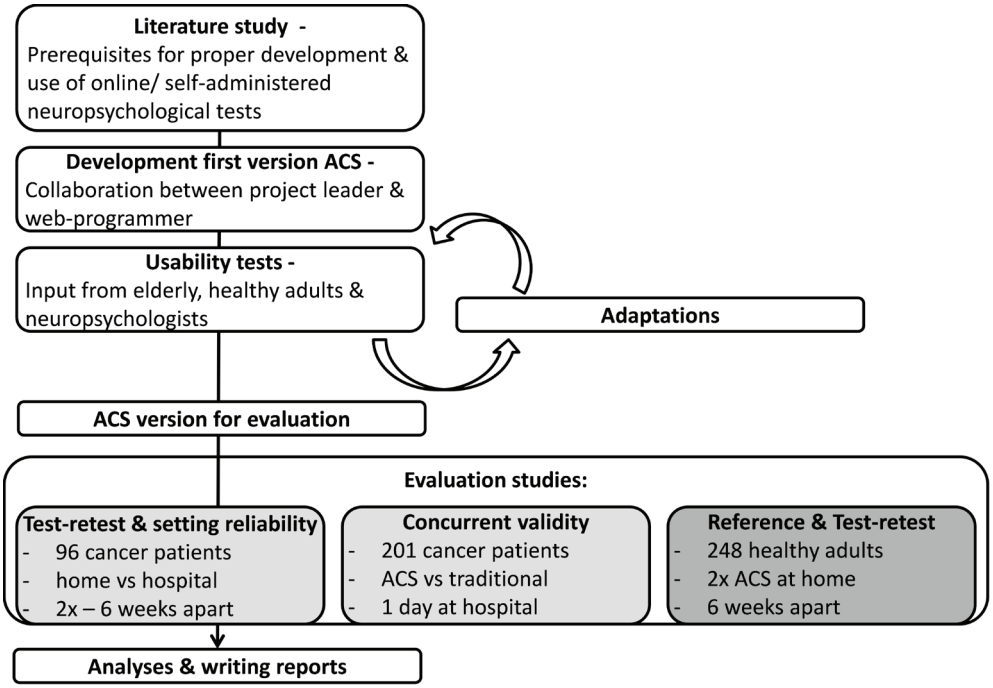

Figure 4. Steps for completing development and evaluation of the ACS.

In **Chapter 2**, prerequisites are outlined for proper development and use of online neuropsychological tests. In this chapter we first discuss advantages and disadvantages of (unsupervised) online neuropsychological testing, and, second, identify several technical, contextual, and psychological factors, as well as methods for quality assurance, that should be taken into account to facilitate reliable test results in the unmonitored setting.

After using these prerequisites from Chapter 2 to develop the ACS—our own self-administered tool for online neuropsychological testing—the remaining chapters report on studies evaluating the ACS.

Chapter 3 reports on the psychometric properties of the ACS measures for use in adult cancer patients. The studies in this chapter evaluate (1) test-retest reliability and the influence of test setting (home or hospital) on ACS performance and (2) concurrent validity (by comparing results from the ACS with traditional neuropsychological tests).

In **Chapter 4**, we present reference data from a sample of healthy Dutch adults to allow for initial interpretation of ACS performances. More specifically, we (1) evaluate test-retest reliability, (2) explore influences of computer familiarity, and (3) present multiple regression-based formulas for calculating demographically (age, gender, and/or education) corrected norm scores.

In the context of future international use of the ACS, **Chapter 5** reports on the development and validation of the English version of the ACS for North American populations.

In **Chapter 6**, we use the ACS to evaluate current criteria for determining cognitive impairment in cancer patients. We argue that more nuanced methods for interpretation of neuropsychological tests scores are needed to improve the diagnostic process of patients, as well as research efforts into the untoward cognitive effects of cancer and cancer therapies.

Finally, **Chapter 7** provides a general discussion of this thesis in which I summarize our findings, place them into context, and suggest future directions for research as well as for neuropsychological testing in general.

Overall, with this thesis I aim to provide a thorough report on the possibilities for using self-administered assessments to gather (reliable) cognitive data, as well as report on the development and evaluation (psychometric properties and norm data) of an online neuropsychological test battery.