# **Master Thesis**

# To evaluate the usability of the ICF core set for HSCT patients, from the perspective of nurses: a feasibility study

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### **Abstract**

Background: After patients undergo a haematological stem cell transplantation (HSCT), they experience symptoms which affect their perceived quality of life. However, current healthcare focuses mainly on curing the disease. The International Classification of Functioning, disability and health (ICF) can be an appliance for nurses to focus on all aspects of a patient's health, including functioning. A core set for HSCT patients has been developed and is ready for testing in daily practice.

Aim: The aim of the study is to evaluate the ICF core set on its feasibility for nurses in care of clinical HSCT patients in a university hospital and to quantitatively explore the use of the ICF core set categories.

*Methods:* This study uses a qualitative-dominant explanatory mixed methods design. Quantitative data regarding the use of the ICF core set categories with HSCT patients are collected. The qualitative part consists of semi-structured interviews with haematological nurses.

Results: The results indicate that using the ICF core set for HSCT patients, to provide information about patients' functioning, is feasible. This information is significant for multidisciplinary meetings and may impact clinical decision-making. The ICF provides awareness to patients regarding important aspects of their daily lives. The top 30% of the most used ICF categories were included in the core set for HSCT patients, except for medication (e110). Energy (b130) was most registered.

Conclusion: From the perspective of nurses, all core set categories are determined to be relevant and useful in gaining information regarding functioning. Applying the ICF core set with the anamnesis and the daily consultations contributes to this information. Further research is needed to focus on the perspective of HSCT patients using the ICF core set.

MESH terms: ICF core set, stem cell transplantation, feasibility, functioning.

# Samenvatting

Achtergrond: Patiënten die een stamcel transplantatie hebben ondergaan (HSCT), ervaren naast medische klachten, ook psychosociale klachten. Desondanks is de gezondheidszorg primair gericht op het genezen van ziekte. De International Classification of Functioning, Disability and Health (ICF) kan de hematologische verpleegkundigen helpen zich gedurende de zorgverlening ook te focussen op functioneren. Een ICF core set voor de HSCT patiënt is ontwikkeld en gebruiksklaar om getest te worden in de dagelijkse praktijk.

Doel: Het evalueren van de bruikbaarheid van de ICF core set bij verpleegkundigen die zorg verlenen aan HSCT patiënten in een Universitair Medisch Centrum en het exploreren van het gebruik van de ICF categorieën.

*Methode:* Een kwalitatief-dominant mixed methods design is gebruikt. Kwantitatieve data over het gebruik van de ICF core set-categorieën is verzameld met behulp van een mHealth tool. Kwalitatieve data is verzameld met semi-gestructureerde interviews bij tien hematologie verpleegkundigen.

Resultaten: Gebruik van de ICF core set voor HSCT patiënten levert gestructureerde informatie op die betrekking heeft op het functioneren van HSCT patiënten. Deze informatie geeft een completer beeld van de patiënt en bleek essentieel in het multidisciplinaire overleg en in klinische besluitvorming. Daarnaast worden de patiënten zich meer bewust van belangrijke aspecten omtrent hun functioneren. De top 30% meest gebruikte ICF categorieën behoren allen tot de ICF core set voor HSCT patiënten met uitzondering van medicatie (e110). Energie (b130) was de meest geregistreerde ICF core set categorie.

Conclusie: Het toepassen van de ICF core set met een anamnese en dagelijkse gesprekken levert bruikbare informatie op over het functioneren van een HSCT patiënt. Uit de interviews bleek dat alle categorieën van de ICF core set relevant en bruikbaar zijn in de dagelijkse praktijk van een hematologie afdeling. Verder onderzoek is nodig om ook het perspectief van de HSCT patiënten te onderzoeken.

MESH termen: ICF core set, stamceltransplantatie, feasibility, functioneren.

# Introduction

More than 50 000 Haematopoietic Stem Cell Transplantations (HSCT) per year are reported worldwide, and approximately 20 000 of these take place in Europe.<sup>1</sup> Stem cells can be harvested from the patient (autologous) or from a matched donor (allogeneic)<sup>2,3</sup> and are dosed by an intravenous infusion.<sup>4</sup> Stem cell transplantation is a treatment option for haematological malignancies as well as a number of other malignant and nonmalignant diseases.<sup>3</sup> The side effects of stem cell transplantation are medical symptoms like infections and organ dysfunction.<sup>5</sup> Furthermore, there are side effects with impact on the perceived quality of life, such as fatigue, anxiety, depressive symptoms, and sexual dysfunction.<sup>6,7</sup>

The primary aim of HSCT from a medical perspective is to improve one's health by curing the disease. However, the health of a patient after a stem cell transplantation (HSCT patient) also includes his or her experienced physical and psychosocial functioning.<sup>5</sup>

Therefore, healthcare provision of HSCT patients should be focused on functioning as well.<sup>8</sup>

The International Classification of Functioning, Disability and Health (ICF) is an appliance that may be used to focus on functioning and supporting patients' self-management.<sup>9</sup>

The World Health Organization's (WHO) conceptual model of health (fig. 1) includes the ICF and the International Statistical Classification of Diseases and Related Health problems (ICD).<sup>10</sup> The ICD classifies health condition, whereas the ICF classifies functioning. The ICF provides a standard terminology to identify patients functioning in all aspects of life.<sup>10</sup> Functioning pertains to how people function in everyday life, in the performance of activities and in the areas of life in which they participate. Functioning is conceptualized as a result of the dynamic interaction between a health condition (disease or disorder) and contextual factors (environmental and personal factors).<sup>10</sup> The ICF uses five components when classifying functioning: Body Functions and Structures, Activities, Participation, Personal factors and Environmental factors.<sup>10</sup> Personal factors are currently being developed.<sup>11</sup> The ICF is complementary to the ICD; both classifications are essential in completing the description of health.<sup>10</sup>

The WHO's conceptual model of health is based on a biopsychosocial model. Using this model shifts the focus of healthcare from disease (biomedical) to disease and functioning (biopsychosocial). <sup>10,12,13</sup> Functioning and the biopsychosocial approach fit the nursing profession in particular because of the profession's holistic orientation. <sup>9,14</sup> Moreover, using the ICF will facilitate nurses and professionals of other disciplines to be effective partners in multidisciplinary teams because of the ICF's standard terminology. <sup>15</sup> Implementing the ICF may be a first step in delivering healthcare with a biopsychosocial approach in which functioning is the focus of health care. <sup>9</sup>

The ICF includes more than 1450 categories. Each of these categories describes an aspect of functioning. For example: work or sleep. Every ICF category has a code, such as b134 (sleep) or d845 (work). These codes are referring to the components of the ICF.<sup>23</sup> To make the ICF feasible in daily practice, core sets are developed.<sup>16,17</sup> Core sets are selected sets of ICF categories related to a specific health condition.<sup>18</sup> For example, there are core sets for hearing loss<sup>19</sup>, head and neck cancer<sup>20</sup> and stroke<sup>21</sup>. HSCT patients lacked a core set and thus a development project began in 2015 in the Netherlands.

Following the guideline for the development of an ICF core set, a content analysis, a literature review and a Delphi study are conducted.<sup>22</sup> Currently, the first version of the ICF core set for HSCT patients needs to be tested in clinical practice. Additionally, the use of the ICF categories must be explored to examine the relevance of the ICF core set categories in clinical nursing practice.<sup>23</sup> A feasibility study from the perspective of nurses is performed, since nurses are the primary health care professionals involved in patients' functioning.<sup>24</sup>

### Aim

The aim of this study is to evaluate the ICF core set on its feasibility and to perform a quantitative exploration of the use of the ICF core set categories by nurses in care of haematological patients hospitalised for autologous and allogeneic stem cell transplantation.

### Method

### Design

A feasibility study was performed, to determine the usability of the ICF core set for HSCT patients. <sup>25</sup> A qualitative-dominant, explanatory mixed methods design was used to gain insight into the usability with both quantitative and qualitative data. <sup>26</sup> First, longitudinal quantitative data were collected concerning the use of the ICF core set categories. Second, generic qualitative data were collected to ensure the discussion of specific topics related to the feasibility and the use of the ICF core set categories. <sup>26</sup> Qualitative data of experience logs of nurses were collected to minimise the recall bias. <sup>26</sup>

### Population and domain

The study population consists of haematology nurses and patients hospitalised for stem cell transplantation in the department of haematology in a university hospital in the northern parts of the Netherlands. Registered Dutch speaking nurses with a minimum of one year of haematological experience were included. This was a purposeful sample to ensure a collection of data with different perspectives regarding the usability of the ICF core set. The sample had maximum variation in age, work experience and experience with the ICF core set. Surses were not eligible if they took care of fewer than two patients during the test period. A convenient sample of all patients hospitalised for stem cell transplantation on January 16th and March 31th 2017 was included in the study.

### Data collection

The quantitative data related to the use of the ICF categories were collected with an mHealth application.<sup>27</sup> The data were extracted twice: at the mid and the end of the test period. Data were collected on: the frequency of ICF categories, the value of the ICF categories (negative, normal and positive), and the goals (the intended achievements of a patient).

The qualitative data were collected by an mHealth application and by interviews. Nurses reported their experiences of the anamnesis and the daily consultations in the log of the mHealth application.<sup>27</sup> Semi-structured interviews with nurses (N=10) were conducted by researcher JB to ensure detailed information about the use of the ICF core set for HSCT

patients.<sup>26</sup> The interviews used an interview guide (table 1) and were performed in March and April 2017. The interview guide contained four focus areas preferred for this feasibility study: acceptability, practicality, implementation, demand.<sup>28</sup> The quantitative data regarding the use of ICF core set categories were added to the interview guide (fifth topic) to ensure the discussion of the use of the ICF core set categories. The data collection continued until saturation of data was reached.<sup>26</sup>

### Data analysis

The quantitative and qualitative data were analysed separately. Quantitative data were analysed using the software SPSS24 (IBM Corporate, New York, United States) and SAS (SAS Institute, North Carolina, United States). The frequency of the ICF categories used and the goals made, were analysed with descriptive statistics. The associations between the ICF categories used were analysed with a chi square test because the association is measured between binary variables in a two by two table. Effect sizes (Phi  $(\phi)$ ) were calculated and assessed against Cohen's criteria  $(\phi~0.1 = \text{small}, \phi~0.3 = \text{medium}, \phi~0.5 = \text{large})$ , using a Fisher exact test to determine statistical significance by the p-value. Pearson correlation coefficient was used to analyse the association between the 30% most used ICF categories and baseline characteristics such as age and hospital duration. An independent t-test was utilized to analyse whether gender and kind of transplantation differ in terms of the top 30% most used ICF categories.

Qualitative data was analysed using the software NVivo11 (QSR International, Melbourne, Australia). Deductive thematic analysis was applied to the data and enabled the study to report the experiences and reality of the nurses participating in the test period.<sup>30</sup> This analysis also established the feasibility by means of the preferred focus areas. Table 2 presents the process of thematic analysis. The first interview was independently analysed by researcher JB and discussed with researcher HAS.

### Procedures

Figure 2 presents the timeline of the ICF project. The ICF core set for HSCT patients was tested in a period of ten weeks. Nurses were involved in two roles: (i) five nurses were trained using the ICF core set (ICF nurses), (ii) and the other nurses of the department received information about the ICF core set, but did not use it actively (regular nurses). The tools developed to use the ICF core set included: an anamnesis based on the ICF core set and daily consultations to follow up with the anamnesis. A report of the anamnesis, the daily consultations, and the experience logs were included in the mHealth application.<sup>27</sup> A report of the anamnesis and the daily consultations were added to the patient record to inform the regular nurses.

After five weeks of the test period, the first quantitative data regarding the use of the ICF categories were extracted from the mHealth application.<sup>27</sup> The frequency of the ICF categories and the frequency of the discussed goals were analysed to complete the interview guide. A pilot interview was conducted to enhance the topics of the interview guide. Only some sub questions were improved. The interviews were audiotaped and transcribed. The transcripts of the interviews were matched with the audiotapes. A written member check was performed after the qualitative analysis to determine the authenticity of the results.<sup>26</sup> The qualitative analysis was matched with the experiences logs of the nurses to prevent recall bias. The remaining quantitative and qualitative data of the mHealth application were extracted at the end of the test period.<sup>27</sup>

### Ethical issues

The study was assessed to be non-WMO compliant and was conducted according to the principles of the Declaration of Helsinki. The nurses were first recruited by email. Next, to improve the study sampling, the regular nurses were asked in person. They signed an informed consent before the interview. The patients signed a general informed consent before hospitalisation. All data was anonymised and stored on a secure USB stick and the secured hard drive of the hospital. Only researchers HAS and JB had access to the data.

# Results

Ten nurses participated in the qualitative part of the study. Table 3 presents the background characteristics of the nurses. No significant differences were found between the background characteristics of the ICF nurses and the regular nurses. A thematic analysis of the interviews resulted in 42 nodes, divided into 10 topics. The 10 topics were linked to the existing focus areas: use of ICF categories, practicality, demand, acceptability and implementation.

During the test period, 27 patients were hospitalised. Three patients refused to participate. The quantitative part of the study included 24 patients. Table 4 presents the background characteristics of the patients.

### Use of ICF categories

In the test period, 1810 ICF categories (100 unique ICF categories) are used by patients. Table 5 presents the most used (top 30% = 17 ICF categories) ICF categories. These most used ICF categories, except medication (e110), are included in the ICF core set for HSCT patients. Out of the most used ICF categories, 11 categories belong to the component of Body Functions and Structures, three to Activities and Participation, and three to Environmental factors. Energy (b130) was the most used ICF category (n=40). A total of 52 goals were made by the most used ICF categories.

Associations between the most used ICF categories are shown in table 6. Handling stress (d240) is significantly positively associated with family relationship (d760) ( $\phi$ =.60, p<0,05), sleep (b134) ( $\phi$ =.73, p<0,05) and pain (b280) ( $\phi$ =.56, p<0,05). Family relationship (d760) is also significantly positively associated with sleep (b134) ( $\phi$ =.63, p<0,05), support of immediate family (e310) ( $\phi$ =.60, p<0,05) and immunological system functions (b435) ( $\phi$ =.60, p<0,05). Handling stress (d240) and family relationship (d760) are the most frequent significantly associated categories. This means that more problems or strengths in one category are associated with more problems or strengths in another category. Moreover, the frequency of the most used ICF categories significantly increases with longer hospitalization (r=0.43, p=0.03). The other background characteristics, gender and kind of transplantation, did not differ in terms of the top 30% most used ICF categories.

In contrast to the quantitative analysis demonstrating that some categories are more relevant than other categories, the qualitative analysis showed that all ICF core set categories are found to be relevant for the HSCT patient. Nurses explained that the reasons for different levels of relevancy included (i) the stage of disease, (ii) expectations of the patient, and (iii) impact of the disease. "Yes, all of these ICF categories are relevant, but not in every moment of the disease" (V7 regular nurse). Another nurse stated: "Preparing meals"

(d630), is not relevant during the admission period, that's only applicable at home" (V1 ICF nurse).

### Practicality of the ICF core set

From the qualitative analysis, anamnesis and daily consultations are found to be feasible. The new ICF related anamnesis was experienced as a good start of the admission. However, it is time consuming. "The time and energy you spent on the anamnesis, pays off during the admission [...] it causes less questions and uncertainties by patients later on" (V10 regular nurse). The daily consultations are experienced as profound conversations and result in valuable information. Nurses' opinions regarding the frequency of daily consultations depend on changes in patients' condition or functioning. Most nurses mentioned the optimal average frequency of daily consultations being two or three times a week.

Some difficulties were found related to the use of the mHealth application, especially regarding to loading speed (related to the internet connection) and clarity of the information regarding admitted and discharged patients. "The overview is not very clear, you can't see who and when information is reported" (V9 ICF nurse).

### Demand for the ICF core set

In the qualitative section of the study, the demand for using the ICF is analysed from patients' perspective and nurses' perspective. From patients' perspective, using the ICF allows: (i) patients to receive more attention, (ii) have their needs discussed more frequently, and (iii) give nurses the ability to act on these needs. "The ICF nurse is able to sit down and take some time for a patient. Patients experience this like: "They have time for me, they listen to me." They can try to find a solution for the patients' needs" (V3 regular nurse). The daily consultation creates more awareness about what is important to the patient. This supports self-management and 'patient-centered care'. "The ICF can help the patient to structure their daily lives. What needs to be done and what is required? What can the patient do by himself and where does he need help?" (V5, ICF nurse).

From nurses' perspective, demand for using the ICF can be found in improved communication between nurses, physicians, and other disciplines. "You are able to support your professional input, patient needs are shown more clear" (V10, regular nurse). A nurse stated: "With the ICF framework we can provide relevant information related to patients' daily life in professional terminology. This has an impact on the communication with physicians" (V1 ICF nurse). This is also reflected in multidisciplinary meetings. "The nurse is presenting the patients' information in a clear structure, so that everything is discussed" (V6 ICF nurse).

### Acceptability of the ICF core set

The acceptability of the ICF was discussed in two aspects of healthcare: health care provision and the relationship between nurse and patient. Using the information from the daily consultation, nurses can anticipate potential problems earlier on, consult other disciplines and determine appropriate health care provision. "With one patient, for example, the issue of continuing his treatment was clarified by the daily consultations to both nurses and physicians. As a result, the patient was discharged to go home and die" (V4 regular nurse). The regular nurses have experienced the ICF project as a valuable addition to patients' regular care. "I see it as an addition […] it creates a better picture of the patient" (V4 regular nurse).

The ICF project adds value to the relationship between patients and nurses. The availability of the ICF nurse in daily consultation results in continuity of the patient care process. "Continuity [...] that you really know the patient from admission until discharge" (V8 ICF nurse). As a result, a trust relationship between a nurse and the patient develops with more in-depth conversations related to functioning. "You need to create a trust relationship. The more you talk to them, the more they tell you" (V9 ICF nurse).

# Implementation of the ICF project

The implementation of the ICF project experienced facilitators and barriers. There are two facilitators of the implementation indicated by ICF nurses and regular nurses. First, the ICF nurses stated that the close contact between them and researcher HAS was helpful in introducing the concept of functioning and reporting functioning correctly in standard terminology of the ICF. Second, the regular nurses indicated that the availability of the ICF nurses was complementary to the regular care. The ICF nurses reduced the workload. "I liked it, it eases the workload" (V3 regular nurse).

The most significant barrier was the vulnerability of the organization. "*Illness of the ICF nurses or holidays were a disadvantage for the project because it disturbed the continuity. That's a pity"* (V5 ICF nurse). Regular care related to HSCT patients is highly biomedical focused. The nurses' limited time, gives biomedical care more priority at the expense of the ICF project and biopsychosocial care.

To enhance the performance of the ICF project, the nurses stated that expanding the nurses' team is necessary. They explained that time and training is required by using the ICF core set. "There need to be nurses capable to perform ICF consultations" (V3 regular nurse). The most relevant requirement for the project, according to the ICF nurses and regular nurses, is commitment from management. "Both management support and staffing is required. With their support it will become a success" (V8 ICF nurse).

# **Discussion**

The use of the ICF core set for HSCT patients provides information about patients' functioning during the admission on the department of hematology. This information is significant for multidisciplinary meetings and may impact clinical decision-making. The ICF categories structure the communication among the disciplines and facilitate the nurses representing the needs of the patient. Additionally, using the ICF categories in daily consultations makes patients aware of important aspects of their daily lives. Most of the frequently used ICF categories were included in the ICF component Body Functions and Structures.

This study provides meaningful insight into the application of the ICF core set in clinical practice. Following the recommendations of previous studies<sup>31,32</sup>, the current study focuses on how to use the ICF core set in clinical practice. Important facilitators, such as efficiency, managerial support, and coaching were obtained. These facilitators are found in previous studies as well. 31,33 Another benefit of using the ICF core set is regarding multidisciplinary communication. Mainly because the structure of the ICF ensures the evaluation of all aspects of patients' functioning without primary focus on disease and disability, as found in other studies.<sup>34,35</sup> The relevance found of ICF categories related to the stage of the disease is comparable with the study of Scheuringer et al. (2010).<sup>36</sup> They found unique aspects of functioning in the post-acute or long-term context.<sup>36</sup> The ICF components Activities and Participations, regarding the relationship, employment and recreation categories, are used more frequently in the long-term context.<sup>36</sup> However, the current study demonstrates that the relationship and employment categories are also present in the top 30% most used categories in the acute stage of the disease. Furthermore, the results of this study show the frequency of these categories increases with longer hospitalisation. This can be explained by the differences in research methods. Scheuringer et al. (2010) used a survey to determine the ICF categories by opinions of experts.<sup>36</sup> The current study tested the use of the ICF categories in actual clinical practice. Testing the ICF core set revealed the top 30% most used ICF categories. These categories, except for medication (e110), were all included in the core set for HSCT patients. Studies conducted previously to develop the core set for HSCT patients did not determine the category medication (e110).<sup>23</sup> This oversight may have occurred because the content analysis only viewed the daily reports, whereas medication (e110) was reported on a different form. McGrady et al (2014) explain that medication management for HSCT patients is difficult due to their complex medical regimes.37,38

Certain aspects must be considered to interpret the results of the current study. First, due to limited time and practical reasons, such as training and coaching, the study sample

included only nurses from one department of haematology. This can influence the generalization of the results. Nevertheless, to gain a better understanding about using the ICF core set in clinical practice, a scope for one team was recommended.<sup>39</sup> Moreover, it is argued that a 'bottom-up' approach will be helpful for the nurses to own the process and results in a successful implementation.<sup>40</sup> Second, the results of this study were collected with semi-structured interviews in an attempt to collect nurses' expert opinions. Consequently, some of the results, especially those involving the patient, were indirect. However, the use of expert opinions is often useful in the early phase of applying a model in clinical practice.<sup>26</sup> Another limitation was the mHealth application.<sup>27</sup> Disturbances related to internet connection as well as getting a clear overview of patients hampered an easy registration of patients' functioning. Nevertheless, the application provided a reliable way to report the data related to the used ICF categories and to extract the data for scientific research. Intercoder agreement about items and topics by researcher HAS and researcher JB enhanced reliability of the qualitative analysis. 41 Finally, the involvement of an ICF expert (researcher HAS) ensured the content validity and helped the nurses learn the fundamentals and report the ICF categories correctly.31

The study's results may bring implications for the practice of nursing. In the current study, a structured terminology usable for communication among disciplines was in demand in the nursing field. The ICF provides the structure and the terminology. This structured terminology allows nurses to provide relevant information regarding patients' functioning. In addition, the terminology will be recognized by physicians and other disciplines and will result in better communication between nurses, physicians and other relevant health professionals.

# Conclusion

From the perspective of nurses, all ICF categories in the core set for HSCT patients are determined to be relevant and useful in gaining information regarding functioning. Medication (e110) was the only missing category in the core set and should be considered for inclusion. Information related to patients' functioning provides the nurses with better insight into a patient's situation. The ICF core set can also help patients recognize what is important in their daily lives. Applying the ICF core set with the anamnesis and the daily consultations contributed to these results. Further research is needed to focus on the perspective of HSCT patients using the ICF core set.<sup>22</sup> Patients' outcomes related to self-management, patient-centered care, and risk management can be explored as well.

# **Reference list**

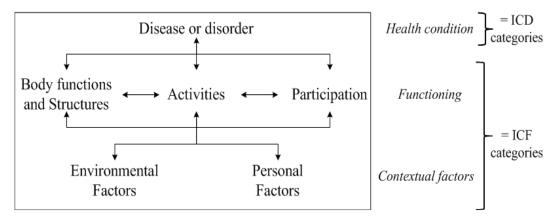
- (1) Gratwohl A, Baldomero H, Aljurf M, Pasquini MC, Bouzas LF, Yoshimi A, et al. Hematopoietic stem cell transplantation: a global perspective. JAMA 2010;303(16):1617-1624.
- (2) Kiss TL, Abdolell M, Jamal N, Minden MD, Lipton JH, Messner HA. Long-term medical outcomes and quality-of-life assessment of patients with chronic myeloid leukemia followed at least 10 years after allogeneic bone marrow transplantation. J Clin Oncol 2002 May 1;20(9):2334-2343.
- (3) Copelan EA. Hematopoietic stem-cell transplantation. N Engl J Med 2006;354(17):1813-1826.
- (4) Ljungman P, Bregni M, Brune M, Cornelissen J, De Witte T, Dini G, et al. Allogeneic and autologous transplantation for haematological diseases, solid tumours and immune disorders: current practice in Europe 2009. Bone Marrow Transplant 2010;45(2):219-234.
- (5) Mohty B, Mohty M. Long-term complications and side effects after allogeneic hematopoietic stem cell transplantation: an update. Blood cancer journal 2011;1(4):e16.
- (6) Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: a review of the literature. Psycho- Oncology 2009;18(2):113-127.
- (7) Hacker ED, Ferrans CE. Quality of life immediately after peripheral blood stem cell transplantation. Cancer Nurs 2003;26(4):312-322.
- (8) Johansson E, Larsen J, Schempp T, Jonsson L, Winterling J. Patients' goals related to health and function in the first 13 months after allogeneic stem cell transplantation. Supportive Care in Cancer 2012;20(9):2025-2032.
- (9) Stallinga H. Human functioning in health care: application of the International Classification of Functioning, Disability and Health (ICF). Groningen: Rijksuniversiteit Groningen; 2015.
- (10) World Health Organization. International Classification of Functioning, Disability and Health: ICF.: World Health Organization; 2001.

- (11) Müller R, Geyh S. Lessons learned from different approaches towards classifying personal factors. Disabil Rehabil 2015;37(5):430-438.
- (12) Jambroes M, Nederland T, Kaljouw M, van Vliet K, Essink-Bot ML, Ruwaard D. Implications of health as 'the ability to adapt and self-manage' for public health policy: a qualitative study. Eur J Public Health 2016 Jun;26(3):412-416.
- (13) Kaljouw M, Van Vliet K. Naar nieuwe zorg en zorgberoepen: de contouren. Den Haag: Zorginsituut Nederland 2015.
- (14) Nathenson P. Application of holistic nursing in the rehabilitation setting. Rehabilitation Nursing 2012;37(3):114-118.
- (15) Kearney PM, Pryor J. The international classification of functioning, disability and health (ICF) and nursing. J Adv Nurs 2004;46(2):162-170.
- (16) Stucki G, Üstün TB, Melvin J. Applying the ICF for the acute hospital and early post-acute rehabilitation facilities. Disabil Rehabil 2005;27(7-8):349-352.
- (17) Stucki G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. Disabil Rehabil 2002;24(17):932-938.
- (18) Ustun TB, Chatterji S, Kostansjek N, Bickenbach J. WHO's ICF and functional status information in health records. Health Care Financ Rev 2003;24(3):77.
- (19) Danermark B, Granberg S, Kramer SE, Selb M, Möller C. The creation of a comprehensive and a brief core set for hearing loss using the international classification of functioning, disability and health. Am J Audiol 2013;22(2):323-328.
- (20) Becker S, Kirchberger I, Cieza A, Berghaus A, Harréus U, Reichel O, et al. Content validation of the Comprehensive ICF Core Set for Head and Neck Cancer (HNC): the perspective of psychologists. Psycho- Oncology 2010;19(6):594-605.
- (21) Glässel A, Coenen M, Kollerits B, Cieza A. Validation of the extended ICF core set for stroke from the patient perspective using focus groups. Disabil Rehabil 2012;34(2):157-166.
- (22) Selb M, Escorpizo R, Kostanjsek N, Stucki G, Ustun B, Cieza A. A guide on how to develop an international classification of functioning, disability and health core set. Eur J Phys Rehabil Med 2014;51:105-117.

- (23) Haasjes J. Human functioning of patients after hematopoietic stem cell transplantation displayed with the International Classification of Functioning, Disability, and Health: a Delphi study. 2016 2016:https://dspace.library.uu.nl/handle/1874/334901.
- (24) Lambregts J, Grotendorst A, van Merwijk C. Bachelor of Nursing 2020: een toekomstbestendig opleidingsprofiel 4.0. : Springer; 2016.
- (25) Arain M, Campbell MJ, Cooper CL, Lancaster GA. What is a pilot or feasibility study? A review of current practice and editorial policy. BMC Med Res Methodol 2010 Jul 16;10:67-2288-10-67.
- (26) Polit D, Beck C. Sampling in Qualitative Research. Nursing Research: Generating and Assessing Evidence for Nursing Practice. Philadelphia: Wolters Kluwer Health/Lippincott Qilliams & Wilkins; 2012. p. 515-531.
- (27) BigMove Institute. eHealth application BigMove. 2016; Available at: https://app.bigmove.nu/. Accessed May/27, 2017.
- (28) Bowen DJ, Kreuter M, Spring B, Cofta-Woerpel L, Linnan L, Weiner D, et al. How we design feasibility studies. Am J Prev Med 2009;36(5):452-457.
- (29) Field A. Discovering statistics using SPSS. 3th ed. London: SAGE publications Ltd; 2009.
- (30) Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology 2006;3(2):77-101.
- (31) Tempest S, Harries P, Kilbride C, De Souza L. To adopt is to adapt: the process of implementing the ICF with an acute stroke multidisciplinary team in England. Disabil Rehabil 2012;34(20):1686-1694.
- (32) Farrell J, Anderson S, Hewitt K, Livingston MH, Stewart D. A survey of occupational therapists in Canada about their knowledge and use of the ICF. Canadian Journal of Occupational Therapy 2007;74(5\_suppl):221-232.
- (33) Reed GM, Leonardi M, Ayuso-Mateos JL, Materzanini A, Castronuovo D, Manara A, et al. Implementing the ICF in a psychiatric rehabilitation setting for People with Serious Mental Illness in the Lombardy region of Italy. Disabil Rehabil 2009;31(sup1):S170-S173.

- (34) Heinen M, Van Achterberg T, Roodbol G, Frederiks C. Applying ICF in nursing practice: classifying elements of nursing diagnoses. Int Nurs Rev 2005;52(4):304-312.
- (35) Tempest S, Jefferson R. Engaging with clinicians to implement and evaluate the ICF in neurorehabilitation practice. NeuroRehabilitation 2015;36(1):11-15.
- (36) Scheuringer M, Kirchberger I, Boldt C, Eriks-Hoogland I, Rauch A, Velstra I, et al. Identification of problems in individuals with spinal cord injury from the health professional perspective using the ICF: a worldwide expert survey. Spinal Cord 2010;48(7):529-536.
- (37) Coleman CI, Limone B, Sobieraj DM, Lee S, Roberts MS, Kaur R, et al. Dosing frequency and medication adherence in chronic disease. Journal of Managed Care Pharmacy 2012;18(7):527-539.
- (38) McGrady ME, Williams SN, Davies SM, Pai AL. Adherence to outpatient oral medication regimens in adolescent hematopoietic stem cell transplant recipients. European Journal of Oncology Nursing 2014;18(2):140-144.
- (39) Verhoef J, Toussaint PJ, Putter H, Zwetsloot-Schonk J, Vliet Vlieland T. The impact of introducing an ICF-based rehabilitation tool on staff satisfaction with multidisciplinary team care in rheumatology: an exploratory study. Clin Rehabil 2008;22(1):23-37.
- (40) Degeling P, Maxwell S, Kennedy J, Coyle B. Medicine, management, and modernisation: a "danse macabre"? British medical journal. 2003;326(7390):649-652.
- (41) Creswell J. Qualitative inquiry & Research design: Choosing among five approaches. 3rd ed. Los Angeles: SAGE Publications Inc.; 2013.

# **Tables and figures**



**Figure 1.** WHO's conceptual model of health representing the interactions between the components (disease, body functions and structures, activities, participation, environmental and personal factors) of the health status. ICD: International Classification of Diseases; ICF: International Classification of Functioning, Disability and Health.<sup>9</sup>

Table 1. Interview guide.

Introduction: What did you ob in daily practice?	serve of applying the ICF core set
Topics	Subtopics
Practicality	Structure, time-investment, usability
Implementation	Design, facilitators, barriers
Acceptance	Positive, negative
Demand	Use of the core set
ICF categories	Frequency, relevance, usability

Table 2. Phases of thematic analysis

Phase	Description
Familiarising yourself with	Reading and rereading the transcripts of the interviews (researcher
your data	JB).
Generating initial nodes	Initial coding after the first interview by two different researchers (JB
	and HAS). The coding was first done on paper, to ensure easy
	consultation between the researchers. After this interview
	researcher JB coded the remaining interviews using Nvivo11.
Searching for themes	Sorting the different nodes into topics. Using schemes to merge the
	topics into the predefined themes: use of ICF categories,
	practicality, demand, acceptability and implementation. This
	process was done with two researchers (JB and HAS).
Reviewing themes	All interviews are performed and the entire data set is reviewed
	again by researcher JB.

Defining and naming Identifying the essence of each theme and determine what aspect of the data each theme captures. Which aspects of the data are most important to reach the aim of the study.

Producing the reports

Writing the report and presenting the results.

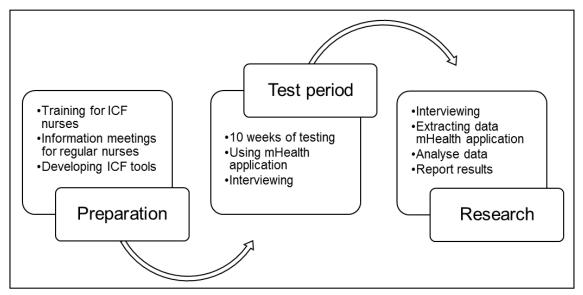


Figure 2. Time line of the project

Table 3. Background characteristics of nurses

1.000**
) 0.421*
0.310*
0.222*
,

<sup>#</sup> International Classification of functioning, Disability and Health, \*\*Fisher exact test, \*Mann-Whitney U Test.

Table 4. Background characteristics of patients

	Autologous-tx# ( <i>n</i> =12)	Allogeneic-tx# (n=12)	<i>p</i> -value		
	(T=12)	(T=12)			
Gender (male) n (%)	9 (75)	10 (83)	1.000**		
Age, years, mean (SD)	60(8)	56 (17)	0.422*		
Hospital duration, mean (SD)	19 (5)	21 (10)	0.573*		

<sup>#</sup> autologous resp. allogeneic transplantation, \*\*Fisher exact test,\*Independent t-test.

Table 5. Frequency of the most used (top 30%) ICF categories

ICF	Coreset*	Description	Frequency	Percent	Goals (n)
code			(Total n=1810)	(%)	
b130	Allo	Energy	40	2.21	10
b525	Allo	Defecation	39	2.15	7
b152	Allo/Auto	<b>Emotional functions</b>	38	2.10	3
b535	Allo/Auto	Nausea	37	2.04	4
b280	Allo	Pain	35	1.93	7
b430	Allo/Auto	Hematological system	33	1.82	1
		functions			
b510	Allo/Auto	Ingestion functions	32	1.77	5
d845	Allo/Auto	Work	32	1.77	0
e110	None	Medication	32	1.77	0
b134	Allo	Sleep	31	1.71	3
d760	Allo/Auto	Family relationship	31	1.71	3
e355	Allo/Auto	Health professionals	30	1.66	0
b455	Allo/Auto	Exercise tolerance	29	1.60	3
		functions			
b250	Allo	Taste	28	1.55	0
d240	Allo/Auto	Handling stress	28	1.55	2
e310	Allo/Auto	Immediate family	28	1.55	1
b435	Allo/Auto	Immunological system	27	1.49	3
		functions			

<sup>\*</sup>Allo=Allogeneic, Auto=Autologous

Table 6. Associations (Phi  $(\varphi)$  correlation coefficient) between the most used ICF categories in patients (n=24)

		b130	b525	b152	b535	b280	b430	b510	d845	e110	b134	d760	e355	b455	b250	d240	e310	b435
Energy	b130	1.00	.54*	.09	02	15	.31	.37	.02	.07	.18	.35	.12	15	.19	03	.40	.19
Defecation	b525		1.00	.08	.34	.16	.07	.24	17	02	.59*	.49*	22	.05	.36	.36	.36	.15
Emotional functions	b152			1.00	08	.25	.00	.00	25	.09	.35	.43	.09	.00	.10	.31	.10	.31
Nausea	b535				1.00	.34	.27	.12	16	02	.47*	.19	15	.34	.27	.47*	.27	15
Pain	b280					1.00	.07	.06	17	19	.41	.26	22	.24	.35	.56*	.15	.15
Hemat. functions	b430						1.00	.49*	10	13	.12	.08	.02	.49*	02	02	.40	.19
Ingestion functions	b510							1.00	.06	.00	.25	.19	06	.20	.07	.07	.07	.29
Work	d845								1.00	19	12	19	.33	34	.15	06	06	06
Medication	e110									1.00	.19	12	.45	45	.24	.03	19	.19
Sleep	b134										1.00	.63*	06	.20	.51*	.73*	.29	.29
Family relationship	d760											1.00	29	.26	.32	.60*	.60*	.60*
Health professionals	e355												1.00	37	.35	10	10	10
Exercise tolerance	b455													1.00	06	.18	.18	.18
Taste	b250														1.00	.50*	.24	01
Handling stress	d240															1.00	.49*	.24
Immediate family	e310																1.00	.24
Immun. functions	b435																	1.00

Note. \*p<0.05 Fisher exact test.  $\varphi$  .10 small effect, .30 medium effect, .50 large effect; bold printed are highly associated with very large effect.