

Annex – Summary

Guide: Practices and recommendations for the management of cognitive impairments after cancer

A French case study in the framework of iPAAC (Innovative partnership for action against cancer), Work Package 4

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Chapter 1. Informing about cognitive impairments related to cancer treatment

Sheet 1.1 Organising information by public authorities

Sheet 1.2 Informing healthcare professionals to improve the care of patients with cognitive impairments

Sheet 1.3 Informing patients as early as possible to promote access to support

MAIN FINDINGS¹

- Very few overarching frameworks (e.g., cancer control programs) include the identification and management of cancer related cognitive impairments
- Despite their potential negative impact on cancer survivors' daily life, cognitive impairments are neither well known nor recognized by most actors, at all levels
- The lack of awareness about cancer related cognitive impairments limit their (early) identification, management and care
- A wider recognition and understanding of the impact of cognitive impairments should lead to consider it as a public health priority on national and European agendas

RECOMMENDATIONS for public authorities

(83 to 100% of the experts have voted in favour of these recommendations)²

- Promoting the initiatives of expert actors on the subject to raise awareness among public authorities
- Ensuring the inclusion of the topic of cognitive impairments in national cancer control programs
- Putting the topic of cognitive impairment among survivorships in the European agenda
- Promoting the inclusion of cancer related cognitive impairments in the work of cancer-related scientific societies or institutions
- Ensuring that health professionals and patients are informed on the basis of scientific information, drawing on tools and practices already available

¹ See Title 3 Chapter 1 of the guide

² See about the workshop Title 2 methodology of the guide and annex 1

CONTEXTUAL FEATURES

- Most health professionals fail in providing adequate information to their patients during consultations
- Public authorities in charge of healthcare and social security organization do not inform about cognitive impairment of patients and professionals in Europe
- The identification and management of cognitive impairment is not integrated yet into every dissemination strategy regarding after cancer care, survivorship and rehabilitation

Examples

Denmark: in the framework of the cancer plan III, cognitive impairments are included in the domain of psychological needs, but no specific interventions are mentioned.

France: the AFSOS makes specific reference for cognitive impairments in adult with non-central nervous system cancer available for health professionals. Information on factors contributing to cognitive impairments, the nature of cognitive impairments, methods for assessing them, strategies for limiting their impact on daily life, and types of interventions available.

USA: dissemination of information via the NCI (National Cancer Institute in the United States) based on the scientific literature and which allows for wide dissemination and easy access on their website, available for health professionals and patients.

Chapter 2. Identifying and objectivising cognitive impairments

Sheet 2.1 Identifying cognitive impairments

Sheet 2.2 Objectivising cognitive impairments

MAIN FINDINGS³

- A majority of cancer patients present cognitive impairments
- Cognitive complaints are underestimated by health professionals
- There is currently no consensus among experts about the tools to identify cancer-related cognitive impairments (i.e., identify cognitive complaints)
- There is a lack of sufficiently sensitive and specific tools to assess cognitive impairments (i.e., To objectivise cognitive impairments), especially for some specific groups of patients (i.e., young patients)

RECOMMENDATIONS for public authorities

(90 to 100% of the experts have voted in favour of these recommendations)⁴

- Organising the identification of cognitive impairments among the supportive care needs
- Organising specific assessment of cognitive impairments
- Including cognitive impairments in tools for identifying supportive care needs
- Encouraging the development of identification and assessment tools
- Defining professionals to whom to refer for specific assessment
- Using validated tools recommended by learned societies

³ See Title 3 Chapter 2 of the guide

⁴ See about the workshop Title 2 methodology of the guide and annex 1

CONTEXTUAL FEATURES

- In most countries, the current pathways of after cancer care do not include the systematic identification and assessment of cognitive impairments
- There are examples of studies having tested identification and evaluation tools which need to be promoted and benchmarked
- There is a lack of organization of the identification and evaluation of cognitive impairments and a lack of tools and trained available health professionals

Examples:

USA: availability in the NCCN guidelines of a distress scale with an item for "memory/concentration"

Denmark: Cancer support needs screening scale used in Danish hospitals with an item for memory/concentration. Used as part of an assessment with a health professional

France: BORA and ALIZEES programs; before the beginning of the rehabilitation, an evaluation is carried out using the FACT-Cog self-questionnaire, the questionnaire, the MOCA screening test and the SDMT.

Belgium: Use of the 17-item CFQ (cognitive failure questionnaire) to assess daily cognitive functioning. Completed before and after the intervention.

Chapter 3. Promoting the different ways of dealing with cognitive impairments

Sheet 3.1 Referring patients to appropriate supportive care

Sheet 3.1.1 Psychoeducation

Sheet 3.1.2 Cognitive training programs

Sheet 3.1.3 Physical Activity

Sheet 3.1.4 Multimodal management of cognitive impairments

Sheet 3.2 Orienting, coordinating and organising the management of cognitive impairments

MAIN FINDINGS⁵

- There is evidence that cognitive impairments can be managed by different type of care, depending on the specific needs
- There is a lack in the availability of supportive care for cancer patients regarding the cognitive impairments that they face
- There are great inequalities among cancer patients in the access to supportive care integrating cognitive impairments management with few local initiatives
- The interventions most widely found in the scientific literature are cognitive training, psycho-educational approaches, physical activity, and multimodal approaches which appear to be the most effective
- Working-age patients and elderlyes should be offered with cognitive support according to their (different) objectives

⁵ See Title 3 Chapter 3 of the guide

RECOMMENDATIONS for public authorities

(76 to 100% of the experts have voted in favour of these recommendations)⁶

- Identifying the resources available on the territory and ensure patients have access to the specific support they need
- Integrating cognitive impairments into the organization and finance supportive care:
 - Encouraging initiatives to set up, develop, and facilitate access to programs supporting cognitive impairments
 - Developing and promote post-cancer care programs that include management of cognitive impairments
 - Organising and implement the management of cognitive impairments in existing organisations

CONTEXTUAL FEATURES

- Currently, not all cancer patients have access to rehabilitation care, especially programs that include cognitive impairments management
- Cancer after care guidelines and organisational framework currently do not integrate the supportive care for cognitive impairments
- Interventions and programs already used in research and clinic are not yet recognised and included in the package of after cancer care
- Cancer patient leagues and associations have strong skills in diffusing the information, promoting, referring patients and offering adequate programs

Examples

France:

- “la Maison Rose” offers psycho-education sessions carried out by a psychologist specialised in neuropsychology
- The cancer center François Baclesse (funded by the Ligue Contre le Cancer) offers computerised cognitive training supervised by psychologist specialised in neuropsychology
- BORA a multimodal program (Lyon), offers psycho-education, cognitive exercises and physical activity in groups of 4 people

Belgium: neurocognitive remediation therapy program (CHU Brugman) offers computerised cognitive exercises and individualised training strategies with group sessions (physical activity and mindfulness)

⁶ See about the workshop Title 2 methodology of the guide and annex 1

Chapter 4. Proposing a management of cognitive impairments in the framework of the assistance to the return to work

MAIN FINDINGS⁷

- Scientific literature demonstrates the impact of cancer and its treatment on work capacity, including cognitive impairments
- The socio-economic burden of work incapacity put at risk the quality of life of cancer patients and the sustainability of social security systems
- More cancer patients in the working age will survive and need to be supported for their (re)integration on the labour market
- The EBCP⁸ mentions the return-to-work of cancer survivors as a priority for the quality of life of patients and families

RECOMMENDATIONS for public authorities

(89 to 94% of the experts have voted in favour of these recommendations)⁹

- Organise return-to-work consultation, including the identification and evaluation of cognitive impairments
- Inform and sensitise the working environment about cognitive impairments and their management
- Ensure the coordination of all actors involved in the return-to-work and the management of cognitive impairments (intra and extramural)

⁷ See Title 3 Chapter 4 of the guide

⁸ The Europe's Beating Cancer Plan (EBCP) available at: https://ec.europa.eu/commission/presscorner/detail/en/ip_21_342

⁹ See about the workshop Title 2 methodology of the guide and annex 1

CONTEXTUAL FEATURES

- Few clinical guidelines and cancer control programs include the issue of return-to-work and its relation with cognitive impairments.
- Few specific vocational rehabilitations focused on cognitive impairment exist for cancer patients, rather general programs and measures for disabled people
- There is a high diversity of actors involved in the return-to-work, but they are not coordinated and have different perspectives
- Cancer follow-up and rehabilitation splits clinical follow-up and support. Thus psycho-social care result in a lack of involvement of clinicians in vocational rehabilitation, of which, cognitive impairments management should be part of.

Examples

Canada:

- Preparation of the return-to-work after cancer treatment. Information Leaflet at the attention of patients¹⁰.

- Supporting Platform for patients, healthcare professionals and employers¹¹

France:

The Ligue contre le cancer and the center of cancer François Baclesse offer programs including psycho-education and cognitive exercises to improve cognitive abilities to return to work

¹⁰

https://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/Prepare_to_Return_to_Work_after_Cancer_Treatment_French.pdf

¹¹ <https://www.cancerandwork.ca/tools/cognitive/>

Chapter 5. Identify the health professionals to be involved in the management of cognitive impairments and train them

MAIN FINDINGS¹²

- Different healthcare professionals can be included in the management of cognitive impairments, such as the psychologist (e.g., specialised in neuropsychology, onco-psychologist), occupational therapist, speech therapist, neurologist, etc.
- Very few initiatives identified that promote multidisciplinary work
- Very few healthcare professionals working with cancer patients have been trained to the identification, assessment or care of cognitive impairments

RECOMMENDATIONS for public authorities

(95 to 100% of the experts have voted in favour of these recommendations)¹³

- Identifying the healthcare professionals who have been trained for the identification, assessment and care of cognitive impairments among (non-CNS) cancer patients
- Organising and promote the training of the healthcare professionals to the identification, assessment and care of cognitive impairments
- Promoting (organise and fund) multidisciplinary teamwork for supportive care after cancer

CONTEXTUAL FEATURES

- Professionals who meet cancer patients are not trained to, at least, the identification of cognitive impairment, but recognise the need to be trained to better support their patients
- The frameworks and prerogatives of most professionals who meet cancer patients do not allow/foresee the identification and management of cognitive impairments

Examples

France:

-University of Caen Normandy: A module in the initial training of neuropsychologists is dedicated to cognitive impairments in cancer

-University of Bordeaux and Rouen: 6 hours of training for speech and language therapists

Belgium: Example of a multidisciplinary teamwork, including a psychiatrist providing medical supervision or oncologist; a neuropsychologist or psychologist trained for example in Cognitive Behavioural Therapy, nurse, social worker and onco-coach (coordinator or nurse referent)

¹² See Title 3 Chapter 5 of the guide

¹³ See about the workshop Title 2 methodology of the guide and annex 1

Chapter 6. Support all aspects of research related to cognitive impairments

MAIN FINDINGS¹⁴

- Cognitive impairments are part of a complex problem involving numerous clinical, socio-demographic and societal parameters requiring a multidisciplinary approach in order to understand and apprehend them
- Research projects have proved to allow the development of evidence-based tools and to test and compare different practices
- Few programs and interventions used in clinical routine are assessed

RECOMMENDATIONS for public authorities

(85 to 100% of the experts have voted in favor of these recommendations)¹⁵

- Supporting the creation of national and international research networks on cognitive impairments among cancer patients
- Encouraging the assessment of current existing practices
- Promoting multidisciplinary and interdisciplinarity research projects on cognitive impairments

CONTEXTUAL FEATURES

- Compared to other field of cancer research, cognitive impairments are under financed and find few research opportunities
- There is a lack of evidence-based guidance on clinical research and in the field, research involving general practice
- Research on cognitive impairment among cancer patients is missing from the European agenda by public authorities; as well as the promotion of good practices exchange

¹⁴ See Title 3 Chapter 6 of the guide

¹⁵ See about the workshop Title 2 methodology of the guide and annex 1

Examples

International:

International Cognition and Cancer Task Force

Europe:

The PanCare network and the European Consortium on cognition and cancer

Portugal:

The CanCOG Cognitive rehabilitation in cancer project¹⁶, offers web-based platform dedicated to cognitive rehabilitation. An international collaboration aimed at translating and adapting the UCLA Cognitive Rehabilitation Intervention Program for Cancer Survivors

Netherlands:

Use of neuropsychological tests in a paper-based to a computer-based format with cancer patients

France:

- CANTO cohort (Unicancer) with a section which aims to monitor the cognitive functions of breast cancer patients in cancer centers (CANTO-Cog)
- We Share, a national patient-centered research platform for cancer researchers and centers, which aims to provide technological tools such as the Equipex to promote the linking of data with a strong social science component. Cognitive assessment will be developed.
- “Axe Cancer et Cognition” of the “Cancéropôle Nord-Ouest” and the Cancer and Cognition platform¹⁷ certified by the ligue nationale contre le cancer which has developed a multidisciplinary program for more than 10 years involving clinicians, neuroscientists, neuropsychologists, statisticians with research programs leading to numerous publications

¹⁶ <http://cancog.web.ua.pt/en/home/>

¹⁷ <http://www.canceretcognition.fr/>