



Mapping met and unmet needs of persons with complex health conditions in the transition from childhood into adulthood with an ICF-based protocol

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Abstract

The transition phase is a critical period in the life of a person with health conditions and complex needs, since the passage from adolescence to adulthood may coincide with changes in functional manifestation of the underlying health condition, changes in social expectations which are met by radical changes in service provision. For this reason a systematic appraisal of functioning of persons sharing diagnostic labels frequently associated with long-term care needs before and after crossing the "transition age" may inform on met and unmet needs and provide guidance to assure continuity of optimal care. A collaborative project named "COTEAM" which gathers partners involved in various stages/levels of care provision for this population in different Italian health service providers was launched Nov 2012. To appropriately describe the functioning profile of a representative sample of the transitioning population we selected five typical situations of potential gaps in service provision: access and orientation in the services, emergency handling, diagnosis, information and update with the latest information on the disease, patient and caregiver empowerment, continuity of care. We selected 39 ICD diagnoses typically associated with long-term care needs. As functioning descriptor ICF was recognized as the best tool to map the functional status and the environment responses for this cohort. Persons encountered by any of the five clinical participating units aged 14 to 20 years between Jan 2010 to Dec 2012 and carrying one of the selected ICD diagnoses have been identified and will represent the population from which a sample of 250 subjects distributed across the entire age span will be selected for the functioning evaluation. The ICF based assessment method (protocol/web application), which has been developed by the Friuli Venezia Giulia Region / Italian WHO-FIC CC, will be employed for the first time out of the Region, in order to verify its usability in describing everywhere the functioning profile of each subject and of a whole sample. The balance between functioning and disability will be evaluated for persons below age 18 and compared to that obtained for persons aged above 18, and will provide a proxy for met and unmet needs. The results of this project will provide the first systematic recognition of the functional profile of persons with disability transitioning from adolescence into adulthood. By offering a reasoned view of met and unmet needs it may be used as a guide in designing models of care minimizing gaps and obstacles in this critical phase.

Introduction

The Society for Adolescent Medicine defined the transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system" (1). Transition from childhood to adulthood, entailing individual and social changes in every domain of life, represents a demanding time for children and for their relatives. Reasonably, it could be even more complex for people with neurological disability, because of the occurrence of psychiatric symptoms that further complicate the management of this phase. Neurological disability can predispose to the onset of concurrent mental disability or interact and influence its persistence, therefore resulting in severe chronic condition.

Adolescents with neurological disability may have a greater need for support and, as consequence, are longer dependent on their parents, are more socially marginalized and can suffer for educational disadvantages and fewer opportunities than their peers (2,3,4).

On the other hand, evidence suggests that the period of transition is perceived from parents of severely disabled adolescents or young adults as a particularly stressful time (5,6,7).

Into this time, several barriers are registered: the difficulty identifying adult primary care providers, resistance and little or no preparation of adolescence and family, lack of institutional support, age rather than indication of maturity or independence as trigger for transition (8,9). Care is often fragmented, specialists rarely communicate with one another and little attention is paid both to physical and psychosocial aspects of disability (2). This make this children, and often their parents, growing up with insufficient knowledge about their neurological disorder and about the service to cope with (10). Even if much literature concerns difficulties in the transition from adolescence to adulthood, little has been written about the impact of severe physical and cognitive impairments in the transition phase. In this poster we describe an ongoing project based on the collaboration of different Italian health service providers launched in November 2012.

Goals of this project are:

- to describe the functioning profile of a representative sample of the transitioning population,
- to examine the way in which continuity of care between child and adult services is assured
- to highlight the met and unmet needs in this process
- to use data as a guide in designing a model of care minimizing gaps and obstacles in this critical phase.

Methods & Materials

Figure 1 - Project phases



The project was organized as in Figure 1:

- 1. Preparatory phase:** we identified 39 ICD diagnoses typically associated with long-term care needs. decision of diagnosis. Selected diagnosis were contained in the following general codes:
 - Neoplasm
 - Endocrine, Nutritional And Metabolic Diseases, And Immunity Disorders
 - Mental Disorders
 - Diseases Of The Nervous System And Sense Organs
 - Diseases Of The Blood And Blood-Forming Organs
 - Congenital Anomalies

We then selected five typical situations of potential gaps in service provision: access and orientation in the services, emergency handling, diagnosis, information and update with the latest information on the disease, patient and caregiver empowerment, follow-up and personalized local care.
- 2. Identification and clinical/functional description of cases:** participating units collected data of patients aged 14 to 20 years between Jan 2010 to Dec 2012 carrying one of the selected ICD diagnoses. For each patient we collected the following data: date of birth, type of admission, source of referral, reason of referral, characteristics of service admission (duration, type and number of interventions carried out) and type of service involved at the time of discharge, if any.
- 3. Description of the current clinical pathway and current needs:** this phase will require participants units to contact selected patients and to submit a semi-structured interview. Collected data will allow us to come to an overall and complete overview of the current patient's clinical condition and to explore activated clinical pathways and met and unmet needs.
- 4. Elaboration of collected data:** we will use a web application developed by the Italian Collaborating Centre that will be employed for the first time out of the Friuli Venezia Giulia Region (11). This application will elaborate for each patient a profile describing the balance between functioning and disability. Profiles of persons below age 18 will be then compared to that obtained for persons aged above 18, highlighting met and unmet needs arising during the time of transition
- 5. Design of a new model:** starting from data, we will design and propose a model of care minimizing gaps and obstacles in this critical phase.

Results

The project took pace in April 2013, and has completed the first phase of patient identification. Up to now, 782 patients were identified (see Table 1).

Out of the whole group, 11% were outpatients, 58% were full time inpatients and the remaining 30% received day hospital treatments.

A first attempt of applying the ICF based evaluation protocol to the whole sample was met with objective difficulties in retrieving the relevant data, in particular those related to the environmental factors, which are in turn critical for the definition of the functioning balance. Acknowledging the importance of a complete and uniform description of functioning, the protocol will be applied to a randomly selected sub-sample of patients who will undergo direct questioning and detailed examination.

Table 1 - Number of patients for each ICD general code

ICD DIAGNOSIS	NUMBER OF PATIENTS
Neoplasm	104
Endocrine, Nutritional And Metabolic Diseases, And Immunity Disorders	40
Mental Disorders	85
Diseases Of The Nervous System And Sense Organs	535
Diseases Of The Blood And Blood-Forming Organs	8
Congenital Anomalies	10
Total number of patients	512

Conclusions

Our experience opens an observation window on the very critical phase of transition. The use of ICF to describe the functioning characteristics of the recruited population, albeit in a small subset, will allow a uniform comparison of data across the transition age, orienting towards the design of a new model for service provision.

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