Lifelong
Learning
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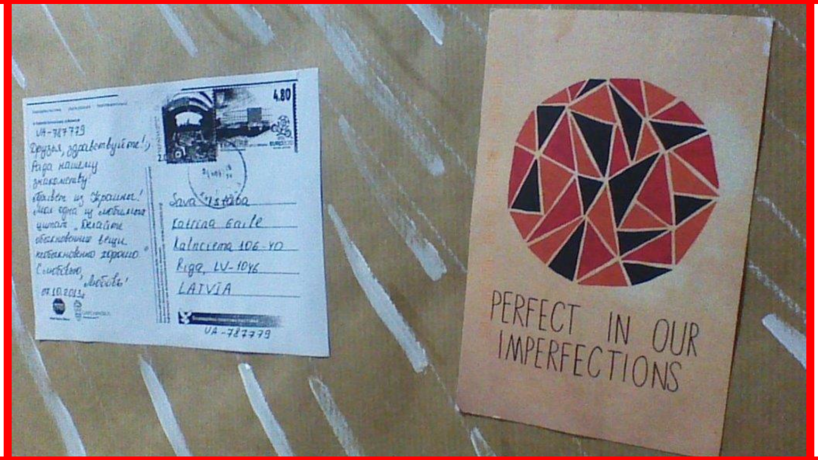
M-CARE

GRUNDTVIG LEARNING PARTNERSHIP
2013-1-RO1-GRU06-29473 1

M-CARE Handbook



A guide for caregivers and professionals

With the support of the Lifelong Learning Programme of the European Union

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PART A. INTRODUCTION TO “M-CARE – MUTUAL CARING–FROM KNOWLEDGE TO ACTION”

A.1. BACKGROUND

The concept behind the MUTUAL CARE APPROACH focuses on the interpersonal care-dependent person or carer-patient dynamics where there is a mutual exchange of care between the carer and care recipient, in contrast to the conventional approach to carer-care recipient relationships where care is provided by the carer to the cared person.

The PROJECT BASIC PREMISE is that MUTUAL CARING KNOWLEDGE AND TRANSFER (routines and ways of coping developed by families through both the caring person and the affected person are looking after each other) can provide the basis for an innovative learning approach in a joined up work between those in need and disability/social/healthcare services, and for development of the capacity of local/national authorities to respond to the needs of these groups of people.

The project is supported by the Grundtvig Programme. The objective of this project is to raise and train educative/social/health knowledge and competencies for affected patients and their caregivers, and to understand, define, develop and promote good practices in supporting families to plan for a future where a person with chronically ill/disabilities is providing care to their elderly carers through the concept of ‘mutual caring’; by this work we’ll advocate to redefine the terms ‘care’ and ‘dependency’ into ‘mutual care’ and ‘interdependency’. It is an innovative approach in which teachers/learners are both people with personal experience of disability/illness and care/education specialists.

A.2. MOTIVATION FOR M-CARE PROJECT

There is an abundance of projects and initiatives that target persons with disability and their carers. However challenges and barriers still exist. We have identified some impediments to effective knowledge, care services, education and real inclusion:

A. Most of these initiatives are still constructed, largely subconsciously, within the framework of the dominant world views and paradigms; thereby –to some extent– perpetuating of these ways of being and doing must to be changed. For too long our tendency has been to study and measure problems and to take curative action, instead of examining the underlying causes, imagining how they can be avoided and embarking on the necessary integrated programs of personal and political change.

B. Neither ‘CARE’ nor ‘DEPENDENCY’ has simple, uncontested meanings. Both refer to a range of social phenomena that involve diverse characteristics that extend from physical activities, through the social relationships among individuals and groups, to the mental states or dispositions involved in caring about someone or being dependent. Research and theoretical critiques have suggested that ‘CARE’ does not denote a narrow set of activities or tasks, undertaken without the active engagement of the supposed beneficiary. Instead, ‘CARE’ is a complex concept that (with the exception of forms of self-care) cannot be undertaken by one person alone; it is a daily reality, a set of practices and ways of going about support. Recent studies of care suggest that qualities of reciprocal dependence underlie much of what is termed ‘care’. Rather than being a unidirectional activity in which an active care-giver does something to a passive and dependent recipient, these accounts suggest that ‘care’ is best understood as the product or outcome of the relationship between two or more people.

C. The concept of ‘DEPENDENCY’ too often connotes negative ‘burdens’ and deficiencies on the part of the person needing help, and we argued that the voices of those needing help must be heard as clearly as those who provide it. The ‘individualizing and excluding’ language of dependency should be replaced by recognition of the basic social condition of ‘INTERDEPENDENCE’ and caring solidarity. Recognition of the increased risks of dependence in advanced old age, and of the need for care of those who are dependent, must involve an acknowledgment of HUMAN INTERDEPENDENCIES. Such a concept is not an assertion of interdependency as an alternative nor a negation of dependency, but rather one based on the recognition of ‘NESTED-DEPENDENCIES’ that link those who need support with those who help them and which, in turn, link the helpers to a set of broader supports.

D. The person with firsthand experience will know that care relationships are often MUTUAL, that most people are involved in both receiving and providing care, although perhaps in very different ways. ‘MUTUAL CARING’ means caring for someone who also cares for you. Mutual caring is common in elderly couples, but can also occur if an elderly parent has a son or daughter with a disability or an older person with health needs cares for a disabled grandchild.

More people are living longer than ever before, including people with various disabilities. An increasing number of people with disabilities are still living at home with family carers who are aged 70 or older. The Carers may be parents/ siblings/ grandparents/ close relatives or friends. They have often spent a lifetime care and assistance in a regular and sustained manner without payment, to a person who is frail and/or aged, disabled/chronically ill. Carers are at risk of financial, health and social burden, not only when caring, but when caring comes to an end because significant barriers to reengaging with society. Many do not recognise the skills they have gained through caring.

From our experience of work with caregivers, we found the next priorities for them:
-Carers to be recognized, respected and valued
-Hidden carers to be identified and supported
-Services for carers and the people they care for to be improved
-Carers to be supported to combine caring and education or work

Over time, because the years go, the family carers start needing more support themselves, and families develop routines and ways of coping, that mean that both the older person and the person with disabilities, whether mental or physical, are looking after each other. Often the cared persons are providing regular care for their ageing relatives (shopping, cleaning, cooking, accompanying each other on days out, providing emotional support).

Therefore, without each other's support, neither person would be able to remain living independently within their local community. Thus they reach to meet the above mentioned ‘nested-dependencies’ that characterise ‘exchange-based reciprocity’, which is the basis of mutual care.

But even though the mutual caring among families is increasing, often remains hidden. Some of the main dissatisfactions for people with disabilities which are turn into caregivers include:
-not being recognized for their role as a carer

-many do not recognise the skills they have gained through caring
-not being offered many choices about how support is provided or continuing to care
-lack of information that is accessible and easy to understand about rights as a carer, available support health conditions of their elderly relative
-lack of practical support and benefit advice that could make a big difference with shopping, getting to appointments
-isolation and reduced opportunities for breaks from caring and friendship
-fear of being separated if social workers discover the extent of the mutual caring that is happening
These are issues for many carers but are often more of a struggle for persons with disabilities. And when they surmount, they want to feel proud of helping out and returning the care and support that has been provided to them by their parents for so many years.

Therefore, we found necessary to accomplish the following *educational needs*:
-Redefining the terms ‘care’ and ‘dependency’ into ‘mutual care’ and ‘interdependency’ is not only an appealing linguistic solution to the difficult dilemmas we have considered, but should underlie educational approaches on disability issues
-Extrapolating, MUTUALITY (simultaneously recognizing similarities in one another’s experiences, thinking and feeling/being willing to share them openly, experiencing connectedness, communion and a sense of ‘we) could redesign educational systems to enable learning and transformation, rather than by imposing the learning agendas of others
-By recognition that families and unpaid carers constitute the largest care force, they should be considered as key partners and providers not only in the planning/design/delivery of care, but also in professionals’ education.
-Professional training for all health and social care staff should include a substantial component which relates to unpaid carers as partners in care, carers’ needs and the diversity of the unpaid caring experience; that training should contain carer modules and input from carers and service users.
-Carers and care receivers should be able to access education and training as and when required to support their caring task and help them develop their own skills, knowledge and expertise; these must be maintained and easily accessible to all.

All reasons mentioned above give us the motivation to create this Learning Partnership involving the exchange of knowledge, information, staff and learners across Europe.

This Learning Partnership is focused on motivation and demand, on participants’s needs analysis, setting objectives which are participant-led. This Partnership introduces new concepts, but universally applicable, which can lead to innovative strategies that are sustainable and cost neutral.

Through the development of mutualistic relationships in education and healthcare services our ability to share life/ or learned experiences will increase, for a better collaboration in envisioning and creating a more humane and integrated society.

A.3. AIMS AND OBJECTIVES

The M-CARE objectives were to:
-understand/define, develop and promote good practices in supporting families to plan for a future where a person with chronically ill/disabilities is providing care to their elderly carers through the concept of 'mutual caring'; by this work we'll advocate to redefine the terms 'care' and 'dependency' into 'mutual care' and 'interdependency'
-introduce new concepts/approaches of 'mutuality and resonance', 'collaborative care', "mutual approach'' as the cornerstone in facilitating education, health/social care programs
-identify, collect, share and exchange best knowledge and practices in which each partner has experience regarding mutualistic relationships
-create M-CARE website to offer free resources to carers, patients/people with disabilities and care professionals on how to cope their common problems
-to be a learning experience that will improve our intercultural competencies, learning/training opportunities in EU member countries and organizations
-contribute to EU priorities: access to e-learning opportunities for people with disability, health, lifelong learning even for our elderly learners

We believe that the knowledge that 'mutual care' and 'interdependency' should underlie educational approaches on disability issues and establish that cared/carer needs/perspectives play a pivotal role educational/research/health programs or social inclusion.

The project is supported by the Grundtvig Programme. It started in August 2013 and ended in July 2015. During that period we have organized five Transnational Meetings, four Workshops and an International Conference where we have trained groups of patients, students, care workers to become more knowledgeable in chronic disorders and a better disability management.

To achieve our results we organized an efficient preparatory work (research by case studies, demands/needs analyze), project activities (meetings/workshops/seminars conceptualized for each target group), project outputs (educational/health/social needs analyze for policy recommendations, learning materials, M-CARE printed/on-line handbooks on medical/psychological/nursing issues and accessing services for carers/cared people). We involved all target groups in project activities (planning, meetings, workshops, mobilities), continuous cooperation and evaluation (questionnaires, reports, permanently feedback). We disseminated the project results: all partners assumed a joined-up strategy for the collection of evidence and dissemination of project new concepts and results, using their findings for recommendations in their institutions and other organization, to decision-makers, every participant becoming a project multiplier.

A.4. TARGET GROUPS

The specific target group of the project was people with special needs/disabilities and their carers, healthcare/social workers, teachers, sociologists, psychologists, volunteers. This project introduced an innovative approach in which the teachers/learners were both people with personal experience of chronic long term illness and/or disability and care professionals. The learners (“pupils”) were the members of the volunteer / educational associations in PL and LV, employees/trainees and volunteers of IT and RO institution, academics, postgraduate students and learners of RO and it institutions, the social/professional partners in RO, IT, PL and LV.

UCV RO and TVU IT has used the project activities and outcomes in theoretical/practical activities for the professional training of postgraduate physical therapists, kinesiotherapists, teachers, social workers, sports instructors. Thus, innovative methods and techniques were implemented in the postgraduate Rehabilitation and Occupational Therapy courses and in the continuing kinesiotherapists education.

DGASPC RO and KSZIA PL have integrated the project activities/outputs into their learners’ trainings and adult patients, in their current social, advocacy, clinical, educational programs and campaigns.

EEC LV has integrated project’s learning activities into its current training courses in European diversity education and inclusive approaches for teachers, teachers trainers, educational guides and counsellors, headmasters, school policy makers, psychologists.

PART B.

MUTUAL SUPPORT AND COLLABORATIVE CARE

Background Knowledge – what caregivers/patient need to understand about mutuality, interdependency and "mutual care" approach

B.1. Care, dependence, independence or inter-dependence

Introduction

In the context of the needs for assistance that arise from physical or cognitive incapacities – the care which Parker (1981) termed 'tending' – it is often asserted that those who depend on care have interests, needs and perspectives that are radically different from the people who see themselves as responsible for providing it. As argued in this paper, this is because research and theory on dependency and care-giving have emerged from different theoretical paradigms and proceeded along largely separate lines, with little sense that they are exploring and explaining different aspects of the same phenomenon.

Research on 'care' has exposed to public gaze and to policy what hitherto has been assumed to be an unproblematic and 'natural' female activity. Conversely, the disability activists and writers who have promoted a social model of disability have challenged the language of and the policy focus on 'care', as oppressive and objectifying: these perspectives have also recently begun to penetrate academic social gerontology (e.g. Oldman 2002).

'Dependency' is an equally contested and widely used concept. Although concepts of autonomy and independence have received critical attention, they are nevertheless commonly promoted as the antithesis of dependency and, moreover, as unproblematic and universally desirable goals.

But are 'care' and 'dependency' really distinct phenomena, and what is the relationship between them? Does the need for and provision of care entail a profoundly unequal relationship, characterized on the one hand by disproportionate power, and on the other by powerless dependency (Orme 2001)? Or are 'care' and 'dependency' both multi-faceted concepts which can accommodate a fine rebalancing of power through the recognition of interdependencies? Must a need for care necessarily be a cause of dependency; do the concepts of care and dependency need to be rescued?

These questions will be discussed with reference to the needs for help and support that can arise in old age, and to the 'care' which is provided by formal welfare services and, informally, by relatives and others. The presentation draws on diverse theoretical and policy literature from Australia, Britain and the United States. The paper first outlines the origins of the discourse of 'care' in British feminist academic scholarship and in wider political debate, in order to make explicit the assumptions and meanings which have become attached to the term. It then discusses the complex and contested concept of ‘dependency’, and identifies some challenges to the conventional structuring of ‘care’ and ‘dependency’ as discrete, oppositional concepts, particularly those that arise from demographic changes and from social gerontology and disability writing.

Feminism and the discourse of ‘care’

Research on ‘care’ emerged during the 1970s and 1980s from several concerns of feminist academics: to make visible the nature and extent of the unpaid work carried out by women in the private domains of the family and home; about the assumptions of both the economic and welfare states that this labour was somehow ‘natural’ ; and about the implications for social justice.

Theoretical writing and empirical research explored the position of women in relation to both the family and the state. The assumption that women provide extensive unpaid care for children and other able-bodied and disabled family members was made explicit and elaborated: ‘[Married] women acquire a set of domestic duties which include caring for their children, their elderly or sick relatives and, of course, their husbands’. Initially, discussion focused on the sexual division of labour in the context of childcare and housework, but Finch and Groves (1980) extended this gender analysis to wider areas of public policy. They ‘transformed’ discussion and debate by cutting through ‘the euphemistic language of ‘‘community’’ and ‘‘family’’ to argue that community care was essentially about the care provided by women; and discussed the effects of caring on women’s life chances in terms of equality of opportunities with men’.

A stream, then a torrent, of studies emerged over the next two decades. Feminist scholars argued that as the burden of caring in the home falls on women, community care policies needed to be understood as regressive and patriarchal, effectively transferring responsibility from the state to the family and, within the family, to women. Documentation of the extent of informal care-giving by women and of the personal, material and opportunity costs associated with it, which were not compensated by state support, were central to this approach (Finch and Groves 1980, 1983). Shaped by this paradigm, research focused on the so-called ‘burden’ of care, and documented various ill-effects that could result from caring for older relatives, including stress, limitations and emotional impacts. Because of the intellectual origins in feminist theory and feminist critiques of the welfare state, particular attention was paid to the circumstances of married women of working age. Where male carers were included in such studies, accounts of their experiences were accompanied by evidence that many received more support from statutory welfare agencies than their female counterparts (Arber, Gilbert and Evandrou 1988).

An alternative strand of feminist analysis, with very different normative overtones, emerged in the USA. Rather than emphasizing the negative (‘burdensome’) features of care, a discourse on the ‘ ethic of care’ emphasized its socially positive and desirable features. In particular, this literature highlighted the relationships in which care is given: ‘The ideal of care is thus an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone’ (Gilligan 1984: 73). *Gilligan* identified a distinctive set of moral principles linked to ‘care’ which need to be recognized alongside – distinctive from, but equal to – those of ‘ rights ’ and ‘ justice ’. At one level this ‘ ethic of care’, most evident among women, can be understood as the outcome of a process of moral growth, in contrast with the rule-based, impersonal justice often associated with masculine maturity. Gilligan argued, however, that this gender link is not inevitable: 'Development for both sexes would therefore seem to entail an integration of rights and responsibilities through the discovery of the complementarity of these disparate views' (Gilligan 1984: 100).

Other writers on the ethics of care, such as Noddings (1984), have also sought to lift the concept from its taken-for-granted origins as a 'natural', highly personal and therefore essentially private activity undertaken primarily by women, and to locate it in a wider arena in which relationships, responsibilities and their practical execution are accorded social value. They argued that care is a precondition for justice, and that the right to receive and to give care needs to be thought of as an issue of social justice. Because the relationships in which care is given and received are characterized by vulnerability and disempowerment, they argued that care needs to be subject to considerations of rights and justice, not differentiated from it. This approach has, in turn, been criticized from a post-modern perspective that challenges the search for an over-arching concept (or meta-narrative) of care (Bowden 1997). The argument is that because the ethical dimensions of the concept vary considerably in different contexts (such as motherhood, nursing, friendship, disability and old age), the attempt to elaborate a single set of principles is futile and possibly dangerous.

The discourse of dependency

'Dependency' is also a widely used, strongly emotional, but essentially contested concept, especially in the context of elder care. But while 'care' is a heart-warming concept with a positive valance, dependency is cold and its connotations are almost entirely negative. Those identified as dependent are assumed actively to seek to reverse this status. There have been several academic analyses and critiques of the concept of 'dependency'. This section focuses on three aspects of the debate about dependency: its complex meanings and etiology; its status as an intrinsic individual attribute or a social construct; and the appropriateness (or otherwise) of the negative connotations with which it is commonly endowed. In practice, however, at least some of the analyses and critiques range across these themes.

There is ambivalence about acknowledging that dependency is a normal, indeed necessary, social condition. In private life, 'dependency ties people together. A child who is unable to depend on adults for guidance would be a profoundly damaged human being, unable to learn and deeply insecure. As adults, if we avoided people sicker, older, weaker than ourselves who needed help, we would at best have a circle of acquaintances, not friends ' (Sennett 2003: 111). In the public realm, however, dependency has been made to appear shameful. Like the term 'care', dependency is an ideological as well as a social construct (Fraser and Gordon 1994). The ideological dimension suggests a broader use for the term than simply a descriptor. Fraser and Gordon (1994) identified four 'registers of meaning':

. Economic dependency;
. Socio-legal dependency;
. Political dependency; and
. Moral or psychological dependency

Only rarely is dependency viewed more positively. Applying a typology of dependency to her psychological and social research with older people, *Margret Baltes* (1996) distinguished structural, behavioural and physical dependency. Although the immediate impact of each of these forms may be to deprive an older person of positive agency, each has a different aetiology and calls for different responses. Baltes argued that, while it may be desirable to adopt policies and interventions that eliminate structural and behavioural dimensions of dependency, this is not possible with physical dependency. Instead, she argued that to recognise dependency amongst those who need help as a result of age-related disability is a valuable 'optimising strategy in that it initiates and secures social contact' (Baltes 1996: v). She further argued that seeking and accepting the help of others should be a positive adaptation strategy which protects and maximizes the use of scarce resources and capabilities in other areas of life that have particularly high personal value. In this respect, Baltes 's rejection of a discourse that emphasises the negative aspects of dependency echoes the feminist writings on the ethic of care that emphasize care as involving the positive interweaving of a 'complex, life-sustaining web' of connectedness between people.

Challenges to the discourses of 'care' and 'dependency'

Clearly there are strong parallels, overlaps and causal inter-relationships between the two: caring may be a response to dependency; dependency is characterised by a need for assistance, which may be met through the provision of care; and care can itself create or deepen dependency. Yet the two remain distinct and dichotomised fields, with considerable potential for conflict. In the following section we present two sets of pressures that require a more productive approach: the changing demographic profile of family care-givers ; and younger disabled people's challenges to the dominant concepts and paradigms of dependency and care.

Research on informal care networks (Kendig 1986; Wenger 1994) and other studies of the care of older people, have challenged the foundations on which the oppositional concepts of 'carer' and 'dependent' are constructed. Most significantly, for the purposes of this paper, the visibility of older people (particularly older men) as carers suggests that, in shaping patterns of care-giving, in this age group at least, gender is no longer the most influential factor. Moreover, in the case of older givers and receivers of care, it may also be increasingly inappropriate to distinguish a 'dependent' older person (with a range of personal, health, social and emotional needs) from a 'carer' (who meets those needs). It is likely that both will have some needs; indeed the extensiveness and severity of these may be finely balanced between the two. As one example, the role of dementia in creating needs for care in advanced old age is associated with high levels of stress and depression amongst carers (Melzer et al. 1994).

Current socio-demographic trends therefore call for a revision of earlier analyses which represented caring as a distinctively female activity, associated with 'intimate relations' in the 'private places' of the home and family, and marking the boundary between 'female' and 'male'. The relationships that provide an increasing amount of informal care for older people are clearly shaped both by patterns of reciprocity and obligation, that have built up in long-term relationships and by gender. Research on the experiences of disability and care-giving in younger couples (Parker 1993), and the little that is known about care-giving relationships among older people (Milne 2001), confirm that a rethink of the feminist carer-dependent paradigm is appropriate. Moreover, Baltes's suggestion that the behaviours associated with dependency can be viewed as a positive adaptation also offers insights into the relationships between older people through which they manage their physical or mental limitations and negotiate care-giving and receiving.

Disability writers have also addressed the concepts of 'independence' and 'autonomy'. Independence, they argue, needs to be understood not as being able to perform activities for oneself without assistance, but as being able to exercise control over whatever help is required in order to achieve chosen goals and objectives. For older people, Collopy (1995) made a similar distinction between the process of making decisions (‘decisional autonomy’) and the ability to implement, operationalize and carry out those decisions (‘executional autonomy’). Thus, someone may continue to exercise a substantial level of decisional autonomy, which maintains a sense of self and personhood intact, even though the execution of those decisions may involve others.

Promoting ‘help’ and ‘interdependence’

Shakespeare called for the rejection of both ‘care’ and ‘dependency’. He argued that these two negatively loaded concepts should be replaced by a recognition of human interdependency, and then suggested that the term ‘care’ should be replaced by that of ‘help’, because it suggests the possibility of alternative forms of social support and more informal, community networks and practices (Shakespeare 2000:71). These, moreover, can be underpinned by altruism and friendship – values that arguably give greater emphasis to choice and genuine moral and personal commitment, and which have the capacity actively to engage both recipients and care-givers.

Replacing the terms ‘care’ and ‘dependency’ with ‘help’ and ‘ interdependency’ is an appealing linguistic solution to the difficult dilemmas we have considered. As *Williams* (2001) argued, friendship suggests a meaningful, mutual personal connection, something that should be a feature of any good relationship in which personal support is a feature. Similarly, the concept of interdependence has significant appeal as a social vision, and suggests a universal and positively valorized condition of humanity. The alternative notions of ‘help’ and ‘interdependence’ cannot, however, deal adequately with the problems of inequality and lack of personal capacity that still need to be addressed. Moreover, both terms pose the issue as inter-personal and effectively preclude the role of the state in managing risk and regulating resources and behaviours. If ‘help’ were willingly forthcoming from friends and the community, there would be no requirement for the state to intervene. Nor does an acknowledgement of generalised social interdependence legitimate claims from individuals with particular needs arising from advanced age to have access to the resources required to assist them.

While the idea of *mutual aid* based on values of friendship suggests a pleasing and spontaneous willingness to provide assistance, there is no sense of the need for long-term commitments; nor a sense of urgency, need or priority in establishing claims for assistance. Nor does this approach offer a basis for providing help to those older people whose extreme isolation provides no opportunities for mutual aid (*Lloyd* 2003). This approach, therefore, while initially appealing, suggests a deeper unwillingness to confront the harder issues involved in making political, economic and moral claims for ongoing support.

To argue against using the terms ‘help’ and ‘interdependency’ as replacements for ‘care’ and ‘dependency’ is not to reject the insights that these concepts offer. As Gibson (1998: 205) observed, few deny that members of ever more complex social systems will experience interdependence as a result of their location in multiple, overlapping networks of dependency. Indeed, this could be said to be a fundamental insight underlyingthe sociological analysis of modern social life.

From this perspective, interdependence can be seen as the result of reciprocity between partners, exchanges between dependent actors over time, and the networking of these relations of dependence. In other words, to recognise ‘interdependence’ is not to deny but to acknowledge relations of dependence. *Kittay* (1999: 67–8) spoke of ‘nested-dependencies’ that characterise ‘exchange-based reciprocity ’. Rather than there being an expectation of direct and immediate reciprocation between care-giver and care recipient, the exchange may take the form of a delayed reciprocity or transferred responsibility, with an expectation that the 'chain of obligations linking members of a community' will lead, if the need arises, to others who are in a position to respond. As one African-American woman said when asked to explain her commitment to caring for others, 'what goes round comes round' (Gerstel 1991: 20, cited in Kittay 1999: 68). Building on this idea, we suggest that rather than abandoning the terms 'care' and 'dependency', a more promising approach is to recognize their essentially contested nature, and to rethink and rehabilitate the meanings inherent in the terms. In doing so, it will be necessary to recognize and address the neglected issues of power that infuse both concepts, as Kittay (1999) has done.

Kittay placed considerations of power at the centre of her important recent re-analysis of the concepts of care and dependency. Dependency, for Kittay, is not an artificial or undesirable social condition, but a fundamental and commonplace aspect of the human lifecourse, an aspect of the human condition encountered in early childhood, illness, disability and frail old age. These are periods of 'inevitable dependencies' of the human life course. Cultural, social and moral conditions in different societies and at different points in history shape both the way these dependencies are understood and the social responses to them (Kittay 1999: 29). One result of this, it can be argued, is that in advanced liberal democracies acknowledgement of the reality of dependency is denied though the promotion of an ideal of individual autonomy.

Providing care, the task of attending to dependants, is termed 'dependency work' by Kittay deliberately to emphasise that the 'care of dependants is work… traditionally engaged in by women' (Kittay 1999: 30). She identified those who directly provide such care (whether paid or unpaid) as 'dependency workers', while those whom they assist are termed a 'charge'. (We use this term, like that of dependency work, in accordance with Kittay's usage, but caution against its wider adoption). Kittay identified a paradigmatic form of dependency work in which daily, ongoing, personal assistance is required; she defines this dependency work as labour that requires the three Cs: **care**, tending others in response to their vulnerability; **connection**, building intimacy and trust or sustaining ties between intimates; and **concern**, giving expression to the ties of affection that sustain the connection.

The vulnerability of care recipients arises from their lack of physical or mental capacity. To counter this, moral opprobrium against their domination by the worker is strong, extending into legal sanctions and penalties that, although rare, may be enforced in either civil or criminal law. The vulnerability of the care-giver in turn arises from her social position, including the isolation of the domestic situation; from her readiness to assist ; through her identification with the wellbeing of the charge; and from the moral or legal constraints on her ability to express annoyance or vent frustrations in interacting with the vulnerable charge in ways that are normally acceptable between equals. A special vulnerability of carers therefore arises from their dedication and sense of duty, and from the ties formed through the care recipient's dependence on their work (Kittay 1999: 34–35). As noted earlier, recognition of the vulnerability of dependency workers is a recent development, and the response in Britain and Australia (at least) has been to provide informal care-givers with information, counselling and access to limited financial support and support services such as respite care. Support for paid care-workers, as reflected in typical levels of pay and conditions of employment, remains equally limited.

Kittay's analysis recognises the issues of power and dependency central to an understanding of care. Rather than avoiding the term 'dependency', Kittay shows it to be an important and effective conceptual tool for examining the intersections between those who require assistance and those who provide it. Recognising bodily dependency as the basis of claims for assistance, and identifying a second, socially-created level of dependency as an undesirable (and reversible) consequence of arrangements for the provision of care, does not preclude acknowledging the rights of both care recipients and care-givers to exercise independent decisions and to optimise control over their circumstances. Rather, it provides a sound foundation from which to justify claims for support. In this context, independence is perhaps best understood not as non-dependence – a structural notion that suggests the absence of practical, social or economic ties with another person – but as ‘ relational autonomy’.

Conclusions

Along with the writers reviewed earlier in this chapter, Kittay appears to see care as a one-directional activity, done by one person to another. At times she uses ‘care’ as a verb that denotes the work involved in providing ongoing personal support, supervision and monitoring; at others, it is used descriptively to denote special qualities. Both uses are acceptable, and both conform to Martin’s criteria of the ‘three Cs’. Kittay’s cautious and somewhat ambivalent use of the term care is, however, suggestive of a deeper re-evaluation of the concept.

Neither ‘care’ nor ‘dependency’ has simple, uncontested meanings. Both refer to a range of social phenomena that involve diverse characteristics that extend from physical activities, through the social relationships among individuals and groups and their positions in the transactions of care and dependency, to the mental states or dispositions involved in caring about someone or being dependent. Rather than calling for the terms ‘care’ or ‘dependency’ to be abandoned, there are good reasons to expect that both will continue to be used in policy discussions, research and elsewhere. But neither term should be regarded as having a fixed or rigid meaning. Instead, the range of meanings embedded in both concepts indicates important possibilities and ideals that create opportunities for the active development of practices of human recognition in response to life course imperatives.

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B.2. Disability, Impairment and Handicap

Introduction

"A billion people in the world, 15% of the population, have a disability severe enough that it limits their participation in family, community and political life. Eighty percent of those billion people live in low and middle-income countries, where often access to basic health and social services is limited for all citizens. However, the impact on persons with disabilities is more profound." This was literally the message of World Health Organization (WHO) Director-General Dr Margaret Chan on the International Day of Persons with Disabilities 2014 (IDPD, 2014).

The director added, it is important to resist the temptation to think in terms of 'us' and 'them'. Instead we must remind ourselves that disability is part of the human condition; all of us either are or will become disabled to one degree or another during the course of our lives. Achieving equity in health status for all people is a challenge for public health promotion campaigns. It is critically important to include persons with disabilities within health promotion plans as they experience more chronic diseases at earlier ages. Collection and routine use of disability data for decision making, strengthens health and human services workforce capacity. Accordingly the presence of people with disabilities is needed to be well recognized and accommodated in many target populations for health promotion.

The terms of Disability, Impairment and Handicap encompass a broad spectrum of morbidities. This chapter gives briefly an overview about these three terms with special concern to the role of physical and rehabilitation medicine.

Definitions

Impairment, disability, and handicap are key terms that the physicians must understand to properly evaluate patients and make appropriate recommendations. According to WHO, 1980, International Classification of Impairments, Disabilities and Handicaps (ICIDH) definitions are:

- 'Impairment (I) is any loss or abnormality of psychological, physiological, or anatomical structure or function'.
- 'Disability (D) is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- 'Handicap (H) is a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual'.

Variable definitions were also proposed by other organi¬zations; as those reported by the Social Security Administration and the American Medical Association (4, 5). As an intention to describe the significance of each term clearly, Maness and Khan, 2015 (6) reviewed different references and pres¬ented a model of how to differentiate between the terms and added that the impairment, disability, and handi¬cap terms are not interchangeable.

History

The concept of “disability” has undergone profound changes over the centuries. In the Ancients, disability was conceived as a consequence of sin or guilt, and antique societies tried to hide or kill people considered living example of that sin or guilt.

In Ancient Greece, the attitude of society towards disabled people was largely determined by religious beliefs and popular traditions which considered beauty, physical integrity and mental health as signs of divine grace, while ugliness, deformity and a different way of conceiving reality, such as madness, were interpreted as marks of supernatural punishment, that was not to be cared or changed by any human being.

In Ancient Rome, the IV law of the XII Tables – a group of laws drawn up between 451- 450 AD by “decemviri legibus scribundis” and containing rules of private and public law that represent one of the first written codification of Roman law – was about children disability: “Cito necatus insignis ad deformitatem puer esto” “A child clearly deformed must be sentenced to death”.

We can see a connection between the disease and the will of the gods who, however, were not the only ones responsible for illness and disabilities. The human sins and vices, the attitudes of people considered inadequate to the Roman concept of the “mos maiorum”, could induce mental illness and disability.

In the Middle Ages, the mother was considered the main cause of the deformity of his child. The monstrous child's birth is a mirror of his sins, which can range from a simple adultery to a carnal relationship with the evil forces. She could paid for this with her own life. People with impairment or handicap, however, could move towards medieval towns for begging. They were used to remember to “normal” that leaving away the precepts of God and Church could provoke that physical distortion and punishment. In the same period , however , were created hospitals and charities institutions for people with disabilities . The Medicine and the society had a paternalistic attitude towards illness and disease.

The history of people with disabilities is therefore told as a story of exclusion, a history (more stories) of voiceless. There are multiple and varied readings and explanations of these exclusions that can be given. Foucault investigated the history of madness and mental disorders, with results that can also be applied to physical disability. He analyzed and stressed out the relationships of power that are divided between those who have the ability to give and take away the word, to describe, to control, decide the lives of others, and those who are object to this power of speech, underlying the social disadvantage of illness.

With the advent of the Enlightenment, the concept of disability profoundly changed: it was conceived as an integral part of the non-perfection of nature, therefore to be considered physiological

At the end of the Age of Enlightenment took strength the idea of a possible rehabilitation of the disabled person, and in the twentieth century specialized institutes marked by "re-education" were created.

The Nineteenth century, however, became the century of “assistance” in the form of institutionalization and of an "orthopedic" concept of the disease. There was also the creation of structures called “Asylum”, which did not have a rehabilitative purpose, but where built and organized in order to keep disabled people alive and hidden. In this century the handicap was set as ethical and social problem, but also had to deal with marginalization, sterilization and in some cases extermination.

At the end of the Sixties a lot of movements for the civil and human rights started to study and analyze the world of disability in a critical way, to find different solutions of managing disability, impairment and handicap.

Many intellectuals and activists started to fight for the rights of disabled people, and trying to propose strategies to change the cultural and social stigma of being a person with disability: "…disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people…In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc. Poverty is one symptom of our oppression, but it is not the cause. For us as disabled people it is absolutely vital that we get this question of the cause of disability quite straight, because on the answer depends the crucial matter of where we direct our main energies in the struggle for change. We shall clearly get nowhere if our efforts are chiefly directed not at the cause of our oppression, but instead at one of the symptoms…" (Paul Hunt, Fundamental Principles of Disability, 1975).

The 1976 is considered the year of the birth of the Social Model of Disability, as the reaction against the Medical Model of Disability. The UK organization Union of the Physically Impaired Against Segregation (UPIAS), claimed: "In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society". A fundamental aspect of the social model concerned equality.

From 1980's and thanks to the social model of sociological studies, the concepts of impairment, handicap and disability started to be separated. The social model also relates to economics. It proposes that people can be disabled by a lack of resources to meet their needs. It addresses issues such as the under-estimation of the potential of people to contribute to society and add economic value to society, if given equal rights and equally suitable facilities and opportunities as others. From that time, many other approaches has been studied in the caring of disability. There is an abundance of projects and initiatives that target persons with disability and their carers. However challenges and barriers still exist.

In December 2006, the General Assembly of the United Nations approved the Convention on the Rights of Persons with Disabilities "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (Article 1)". It was a fundamental step, both from a political and a cultural point of view, of a long process that started with the UN Conference of Human Rights in Vienna in 1993 and the UN Standard Rules on Equal Opportunities also in 1993.

The M-CARE Grundtvig learning partnership project conducted by "University of Craiova (RO)", "General Directorate of Social Assistance and Child Protection Dolj (RO)", "The Cracow Centre of the Management and Administration Ltd (PL)", "European Educational Circle (LV)", "Tor Vergata University of Rome: Faculty of Medicine, Clinical Sciences and Translational Medicine Department (IT)", has introduced the **concept of**

Mutuality, as a new approach in the caring of disability, starting from the premise that "mutual caring knowledge and transfer" (routines and ways of coping developed by families through both the caring person and the affected person are looking after each other) can provide the basis for an innovative learning approach in a joined up work between those in need and disability/social/healthcare services, and for development of the capacity of local/national authorities to respond to the needs of these groups of people. This new approach can be read as the cross-link between the Medical model and the Social model of

Disability prevalence

Before going through numbers it is important to denote that prevalence of disability/impairment/handicap depends on different factors including age and accuracy of indicators. Moreover morbidity-compression and morbidity expansion scenarios may even coexist in different population groups, according to their sex or educational level (18). Among various literatures concerned with this aspect, an insufficient recognition of the importance of such factors and the socioeconomic characteristics of the studied populations impedes reliable international comparison; standardization of indicators before measuring prevalence is therefore required.

According to the WHO, more than 1 billion persons worldwide have a disability. Conditions that most often lead to disability include arthritis, back or spine problems, and heart conditions. Common limitations include the inability to walk three city blocks or to climb a flight of stairs. It is worth to mention that the ICF (International Classification of Functioning, Disability and Health), reported that the most impaired functions are sensory functions, pain, and neuro-musculoskeletal and movement related functions; while the most impaired structures are referred to skin and related structures. The most limited activities are general tasks and mobility. The most extended facilitators are referred to products and technology; for barriers are referred to natural environment and human-made changes to environment (20).

Clinical assessment

From a clinical point of view the consultative examination report of people with disability must be consistent with the objective clinical findings found on examination and the claimant's history, symptoms, laboratory study results, and response to treatment. It should include a description, based on the physician's own findings, of the individual's ability to do basic work-related activities instead of a general opinion as to whether the claimant is disabled under the meaning of the law.3030.

A "functional independent medical examinations (IME)" is a model suggested by Clifton, 2006 (22) to enhance the value of both IMEs and the Functional capacity evaluations (FCEs), it combines both models; medical-based examination and a function-based disability evaluation. This combination enhances the assessment of the relationship of pathology to impairment and impairment to disability status especially, in musculoskeletal disorders.

About assessment; evaluation of disability and impairment as ecologic factors that may affect patient`s satisfaction, started to be mandatory, in order to test the degree of functional improvement after conservative therapy or surgical intervention. Johnston and Pollard, 2001 (24), examined whether Impairment, Disability and Handicap can be measured independently and if there is support for the sequential or causal relationship between the three constructs. Data were collected from 101 disabled adults and 108 myocardial infarction and 68 Stroke patients. They concluded that the International Classification of Impairments, Disabilities and Handicaps (ICIDH) model was supported in that D predicted H for stroke, but there was no support for a path between I and D or between I and H. Further it was not always possible to distinguish the three constructs. There is no single functional assessment tool to evaluate D, I, and H. Instead several validated questionnaires that measure permanent functional disability are available within specific areas (25-29) as the examples reported by Maness and Khan in 2015.

Physical and rehabilitation medicine

Physical and rehabilitation medicine (PRM) is a highly interdisciplinary area concerns the limitations of functioning and disability associated with health conditions and with the complex interaction with personal factors and the environment, where rehabilitation resembles as its core strategy (30). Based on the International Classification of Function (ICF), rehabilitation can be defined as the health strategy that “aims to enable people with health conditions experiencing or likely to experience disability to achieve optimal functioning in interaction with the environment” (31). This definition of rehabilitation can serve as reference for conceptual descriptions and definitions of professional disciplines such as the medical specialty PRM, the rehabilitation professions, and distinct scientific fields of human functioning and rehabilitation research (32, 33).

On June 9th 2011 the WHO World Report on Disability (WRD) acknowledges the genuine role of PRM and its contribution to enhancing a person’s functioning and participation in life. von Groote et al., 2011 (34), reported that with this WRD WHO has created a tool to implement central demands of the convention on the rights of persons with disabilities, and that now is the time for PRM to seize this exceptional opportunity to accomplish its role as facilitator to help people with disability to fully participate in life with the optimal level of health.

Rehabilitation measures focus on:

- Prevention of the loss of function;
- slowing the rate of loss of function;
- Improvement or restoration of function;
- Compensation for lost function;
- Maintenance of current function.

The categories of rehabilitation measures as distinguished by WRD:

- Rehabilitation Medicine;
- Therapy;
- Assistive Technologies.

In order to achieve these goals using these measures, the WRD stresses that rehabilitation must always be voluntary and that people with disabilities have to be included into all aspects of decision-making in the rehabilitation process and that furthermore, rehabilitation requires team-integrated action (20, 35-40).

In long-term disabilities the rehabilitation process requires a carefully planned and integrated program with concern to the related psycho-social issues, out of this perspective, the PRM physician management of long-term rehabilitation is a unique contribution; the role of the PRM physician includes provision of medical care, provision of advice on diagnosis, likely prognosis, treatment options and their potential benefits and risks to patient and family.

In case of comorbidities as in majority of the patients appropriate monitoring and therapy is required with active participation of a team of professionals. The PRM physician sometimes needed to be the leader of the team, developing treatment protocols and setting treatment expectations. Takáč P et al ., 2014 designed a figure summarizing the Role of the PRM physician in disability, to readers interested the paper is free full text is available online (42).

A call for a change was sent by Negrini, et al., 2014 (43); about the urgent need for more Physical and Rehabilitation Medicine (PRM) services and how this is faced by the actual research funding. The authors briefly presented the results of an analysis as an interesting case study about research funding by the Italian National Health Service. The topics of potentially greatest interest for aging Western societies, like chronicity, disability and rehabilitation, were among those least often funded and considered in the traditional method of financing research projects. The authors described the research as a selfish monster that eats up the money it is fed, adding a question of repudiation if this is really what our countries need?

About areas of disability for research; examining recent trends in disability and disability-free life expectancy is still on going, little is known about the factors that underlie the reduction in disability over time (44). Krahn et al 2015 (45) recommend future research and policy directions to address health inequities for individuals with disabilities; these include improved access to health care and human services, increased data to support decision-making, strengthened health and human services workforce capacity, explicit inclusion of disability in public health programs, and increased emergency preparedness.

A Global Disability Action Plan 2014-2021 was adopted by the WHO in May 2014 during the World Health Assembly in Geneva, Switzerland (46). The Action Plan included research within the three objectives:

1- To remove barriers to health services and programs;
2- To strengthen and extend rehabilitation, habilitation, and other supportive technology and services;
3- To strengthen data collection and support research on disability and related services.

This Action Plan is a challenge for physical and rehabilitation medicine (PRM); it sets high standards of rehabilitative care and relevant research to develop rehabilitation programs based on a high level of scientific evidence.

Conclusion

Health promotion for people with disabilities is one of the major priorities, setting the balance between personal and community responsibility is important to achieve this goal. Epidemiological studies, research and plans enhancing physical and rehabilitation role are mandatory measures to step forward in the management of Disability, Impairment and Handicap

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B.3. Mental health
Mutual Care Groups in Latvia

We understand mutual care as helping each other, learning from each other in the process of healing. It can manifest itself in a patient-doctor relationship, in a patient-patient relationship, patient-nurse relationship, patient-relative relationship etc. A care giver can be also a relative or friend or a volunteer. Sometimes, patients know so much about their illness, about own body that they can teach valuable details to the doctor or nurse. The question is: are doctors and nurses open to use this valuable information that patients can share? Are patient`s skills and knowledge used in healing other patients? We were searching the answers to these questions.

In the Soviet Union psychiatric patients were isolated, stigmatized, discriminated and spent all their time in hospitals. The attitude towards patients with mental health problems in society was basically negative. In addition, political opponents were kept in psychiatric hospitals to stop them for expressing their opinion. As the result a negative image of psychiatric patients was created in society, they were labeled, laughed at and excluded from healthy and normal “us”. They and their families felt shame and not belonging to the society, being different, being the negative `other.`Holliday et.al. (2004., p.3) define otherization as `imagining someone as alien and different to 'us' in such a way that 'they' are excluded from 'our' 'normal', 'superior' and 'civilized' group.' Mutuality in our opinion is opposite of otherization. Mutuality means seeing the other in positive terms as a resource, as someone from whom we can benefit and learn.

After regaining independence of Latvia in 1991 the situation started to change step by step. It became possible to attend day care centers instead of living whole life in the hospitals, it became possible to get care of a multidisciplinary team consisting of a psychiatrist, a psychologist, a social worker.

After joining the European Union the situation in mental health care has changed, also attitude in the society towards mental health patients is changing step by step and there is less stigmatization of mental health patients. We are experiencing transition from basically medical and medication based model of mental health patient care where patients stay in mental health hospitals and other mental health care institutions for a long time in isolation from society to a new model where patients are kept outside mental health hospitals in ambulatory care as much as possible and integrated in society. With this paradigm change in mental health care in Latvia new institutions based on mutual caring of patients, doctors, care givers and relatives have appeared.

We are experiencing a transition from basically medical and medication based model where patients spend most time in mental hospitals to the model based on personality development, of applying different therapies: group therapies, music therapies, art therapies, ergo-therapies, where patients are involved in society, accepted, integrated in society, participate in different activities in the society, give their contribution to society.

Special job placements are created by European Social Foundation project financing for people with different mental health disorders. Thus, for example, the leader of Self-help group “Pietura dāvana” (Station the Gift) has got a job as a lawyer after nine years long unemployment.

The first support group for patients with mental health disorders and their relatives “Gaismas stars” (The Beam of Light) was founded in 1997. The association “Gaismas stars” was founded to help and support the patients with schizophrenia. Our project partners were lucky to meet with the team of the “Beam of Light” and to see what activities they have organized in their day care center for self-expression and healing of schizophrenia patients (see the photos below). For example, there is a room where schizophrenia patients are designing and sewing different soft toys. In another room of “”Gaismas stars” premises the patients are making ceramic cups for selling. Thus, the patients get opportunity for self-actualization as well as for earning some money.

The association “Gaismas stars” team consists of social workers, social care worker, ergo-therapist, music and art specialists. The team also invites psychiatrist who is organizing training for the family and relatives of the schizophrenia patients. The goal of the training program is to share information and give advice how to behave in situations of crises, explain the treatment process, collaboration of psychiatrist with the patient and the family. It tries to decrease the feeling of shame and guilt , to provide emotional support, to provide opportunity to meet other families with similar problems, to share personal experience.

Some patients also get the job in the day care center with the help of the European Social Foundation financing. For example, one patient with schizophrenia is teaching English to other patients. Thus, it was mutual gain: other patients learn English while she gets opportunity for self-actualization.

Today there are more NGO`s supporting and helping mental health patients such as “Saules zīmes” (Signs of Sun), “Svētā Jāņa palīdzība” (Saint John`s help) and other. “Saules zīmes” was founded in 2013. Its goal is to educate society about mental health disorders, to decrease prejudice and stigma towards mental health patients. The association is a support center and provides psychological, emotional and practical support to the patients with mental health disorders. It organizes support groups for people with depression every week where people can meet in a friendly, informal group of up to 10 people. If they feel sad, hopeless , participation in the group helps them. They spend about 3 hours together, they meet people with similar problems, share their feelings and experience and get to know new information about depression and possibilities of healing it, they get moral support and encouragement, find strength to improve the situation. The group is lead by leader of the association “Saules zīmes” Kristīne Leja and clinical psychologist Nataly Morozova.

Self-help group “Pietura Dāvana”

In 2002 Latvia Psychiatry Nurses association and Latvia Human Rights and Ethnic Studies Centre prepared a methodological material for patients and their relatives as well as for other stakeholders on forming a self-help group. In 2014 psychiatrists and psychologists together with the most active patients have initiated formation of a self-help group “Pietura Dāvana” (Station –the Gift) for patients with mental health problems.

Self-help groups differ from support groups. While support groups are led by health professionals such as psychiatrists and clinical psychologists, the support groups are lead and managed by the patients themselves. In essence the self-help group “Pietura Dāvana” is a mutual help group. This self-help group is led by the mental health patient with bipolar disorders and by other mental health patients themselves, not by health professionals. Self-help group „Station -the Gift ” leader is advertising : writing e-mails, putting advertisements on the walls of the centre, contacting Day Care centre patients who attend Group therapy inviting to join the group, she spreads the leaflets, about the group.

The psychiatrists and psychologists are always here to help and support, they are open to invitations to tell about different aspects of mental illnesses and their treatment and different therapies. Psychologists Ilona Krone, Ieva Bite have helped with advice. Self –help group “Pietura davana” participants spend time together, sometimes organize common events like visiting some participants home and celebrating the midsummer festival together.

The Manager of the Outpatient Center Pārdaugava, Branch of Riga Psychiatry and Addiction Center, psychiatrist Elmārs Tērauds has been so kind to allow the group to meet every Thursday from 14.00 to 16.00 in the cosy group therapy room of the center. The location is 10 -15 min. from Riga center by public transport, so also patients who live outside Riga can attend the group meetings. One participant of the group sums up the importance of the group: “If not in the self-help group Circle meeting, where would I be able to express all my feelings, my problems and doubts?” Only people who share similar problems can understand each other. Their advice is based on personal experience and sometimes it is more useful and practically applicable than advice given by doctors and psychologists. Experiential knowledge is very useful.

Mental health patients are scared to tell their healthy friends and relatives about their feelings and problems because they are afraid that they will not be understood and will be laughed at.

Self-help group practical activities

A self-help group is supporting, educational (oriented on positive change) mutual help and mutual support group of people who have some common problem.

The self-help group participants admitted that the process going on during the group meetings had psychotherapeutic effect on them.

Self-help group participants admitted that time from time they need other patients` emotional support and care and that they feel needed and valued also when somebody needs their emotional support and advice.

Participants support each other, improve quality of life, help in solving problems, visit each other in the hospital. In self-help group patients feel needed, respected, listened to , not isolated they also feel that they can give valuable advice to somebody else from their group, that somebody cares about them, that they can do something valuable, something good to others, they give advice, they support, they obtain new skills and information, get new friends.

The participants can express themselves: by just talking, by active listening, by choosing to be the leader (facilitator for the day round, circle) , by organizing the group.

Help is mutual, the one who helps is also getting help from others, sees that others also have this problem, gets some useful information about healing possibilities, develops initiative, motivation , becomes active and more healthy personality.

Participants can feel secure; they know that always they will get help from other participants. In group meetings they use their skills from previous sessions with psychologists, psychotherapists The group participants go to watch group participants` artists` paintings to his house in Saulkrasti, swim in the sea together. Thus, **the mutual help** group fulfills participants` social needs, communication needs, belonging needs. That is something that just short visits to the psychiatrist and psychologist cannot give the patients. In addition, participants have diverse experiences, skills: mutual sharing of diverse experiences, skills, learning from each other, everybody can feel that can contribute somehow, that his/her contribution is needed for the group. The participants can share feelings, their stories, caring for each other, mutual support, can talk about their worries.

At the beginning of the meeting every participant tells how she/he feels on scale from 1 to 10, what has happened during the week Participation in the group develops participants` ability to collaborate with others, to work in teams, to be flexible, to reorient oneself quickly. Thus, it prepares also for being better employee, for living a better fulfilled life.

Participants can satisfy their self-esteem needs; they can succeed in telling their stories, giving advice, sharing experiences, good practices, some relaxation techniques, writing a letter to oneself, mindfulness activities to get into mindful state.

There are Circle meetings, sometimes with tea. Everybody has chance to contribute and know that other people are willing to help. The chairs are arrange in a semi-circle during the group meetings, the participants tell about their problems, worries complaints. Other participants respond, encourage, sometimes giving advice, if asked. This is a very powerful way of self-expression and mutual caring. The participants follow simple basic rules:

- We are here to support each other for good without any judgement and any interruption while sharing
☐ We treat each other equvalently in dignity
☐ Each of us expresses for himself/herself by using the pattern “me” (only me, my own experience)
☐ Our talks are having time limited boundaries
- The meeting moderation duties can be transfered to the other participant at present
- We do arrive on time
☐ We share just our own experiences
☐ We do avoid any advice giving unless the participant is asking for it specifically

The group meetings are friendly, the goal is to help each other, to share their stresses. The group leader makes jokes and more jokes to get a good atmosphere. Participants develop intimacy is as a result of self-disclosure. The participants make physical contact: hug each other with warmth.

Participation in self-help group empowers patients to take their own destiny into their hands. The participants make physical contact: hug each other with warmth.   The group is free of charge, it is essential as most mental health patients cannot afford the expensive services of private psychiatrists and psychotherapists. Everyone can contribute in the group. There is strong peer influence. Everybody is accepted without judging. Just there is a rule that patients should not come to the meeting after using alcohol or drugs.

In a Circle the participants: 1) tell how they are feeling on scale from 1-10 2) share their worries, hopes , reflect about what happened with them during the week 3) the facilitator sums up on positive note. Every time a different Facilitator is chosen. Every time a different meaningful theme is discussed.

There is enormous potential of the self-help groups for mental health patients : the participants develop a social network, personality develops, they get great satisfaction.

In general psychiatric patients in Latvia show very little initiative for forming self-help groups and the membership in the self-help group was low. Patients need to be informed about self-help groups by doctors and psychologists.

Psychiatrists should inform the patients how valuable their participation in self –help group can be. Teaching about mutual care should be introduced in study programs for nurses, doctors, public health specialists , social workers , care givers, psychologists and other health care specialists.

In Latvia it is a problem to form such a self-help group in countryside, because everybody knows everybody and if somebody is seen in mental health self-help group, they are afraid of labeling, to be laughed at.

Self-help groups can be powerful and very effective in healing psychiatric illnesses; however, their potential is almost not used in Latvia.

To sum up, in spite of the fact that the concept of mutual care is not widely known among health and care professionals in Latvia, there are many good examples of mutual care of mental health patients.

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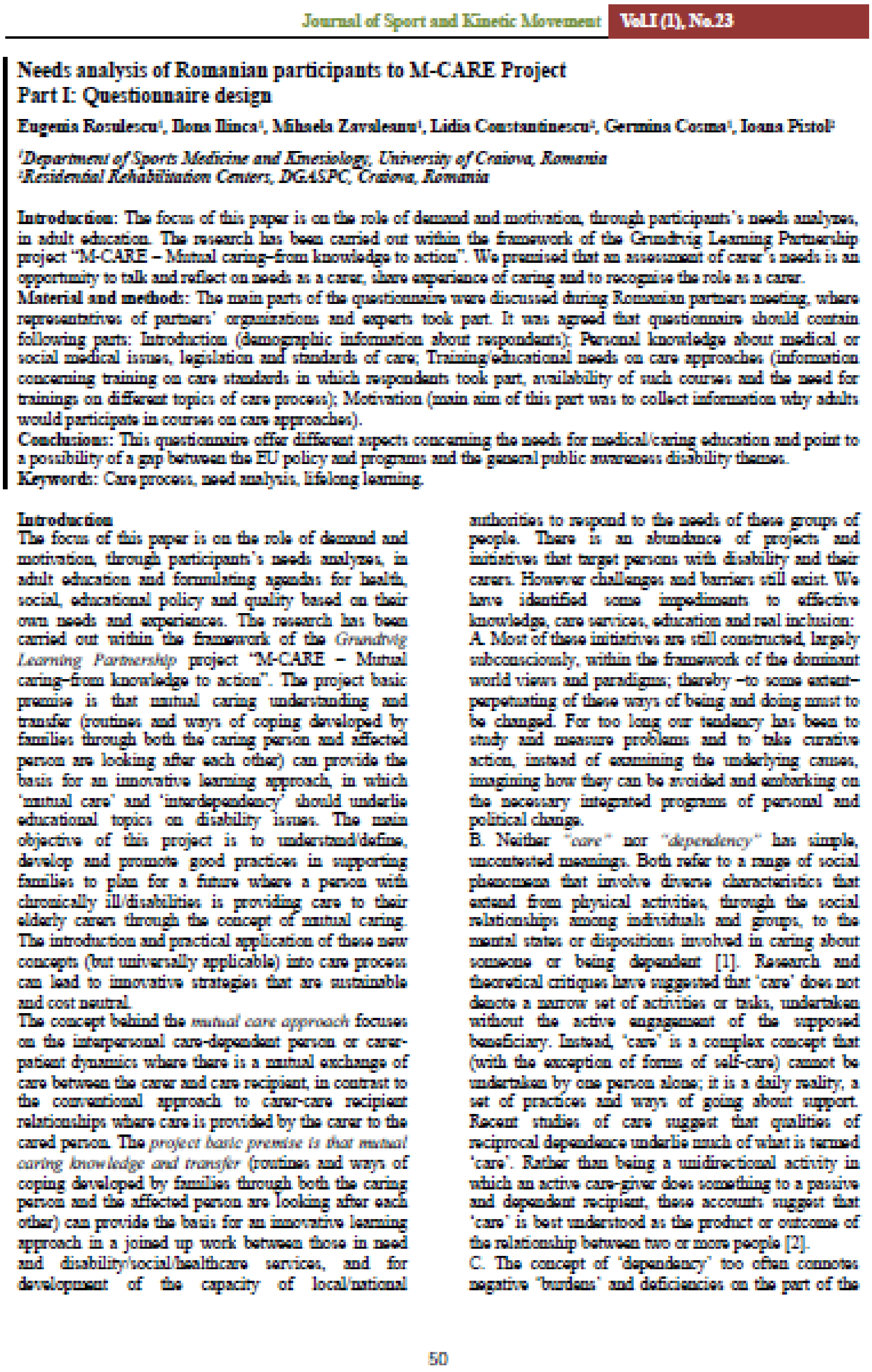
APPENDIX

PUBLISHED M-CARE ABSTRACTS AND PAPERS



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Needs analysis of Romanian participants to M-CARE Project
Part I: Questionnaire design

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Introduction: The focus of this paper is on the role of demand and motivation, through participants's needs analyzes, in adult education. The research has been carried out within the framework of the Grundtvig Learning Partnership project "M-CARE – Mutual caring–from knowledge to action". We premised that an assessment of carer's needs is an opportunity to talk and reflect on needs as a carer, share experience of caring and to recognise the role as a carer.
Material and methods: The main parts of the questionnaire were discussed during Romanian partners meeting, where representatives of partners' organizations and experts took part. It was agreed that questionnaire should contain following parts: Introduction (demographic information about respondents); Personal knowledge about medical or social medical issues, legislation and standards of care; Training/educational needs on care approaches (information concerning training on care standards in which respondents took part, availability of such courses and the need for trainings on different topics of care process); Motivation (main aim of this part was to collect information why adults would participate in courses on care approaches).
Conclusions: This questionnaire offer different aspects concerning the needs for medical/caring education and point to a possibility of a gap between the EU policy and programs and the general public awareness disability themes.
Keywords: Care process, need analysis, lifelong learning.

Introduction

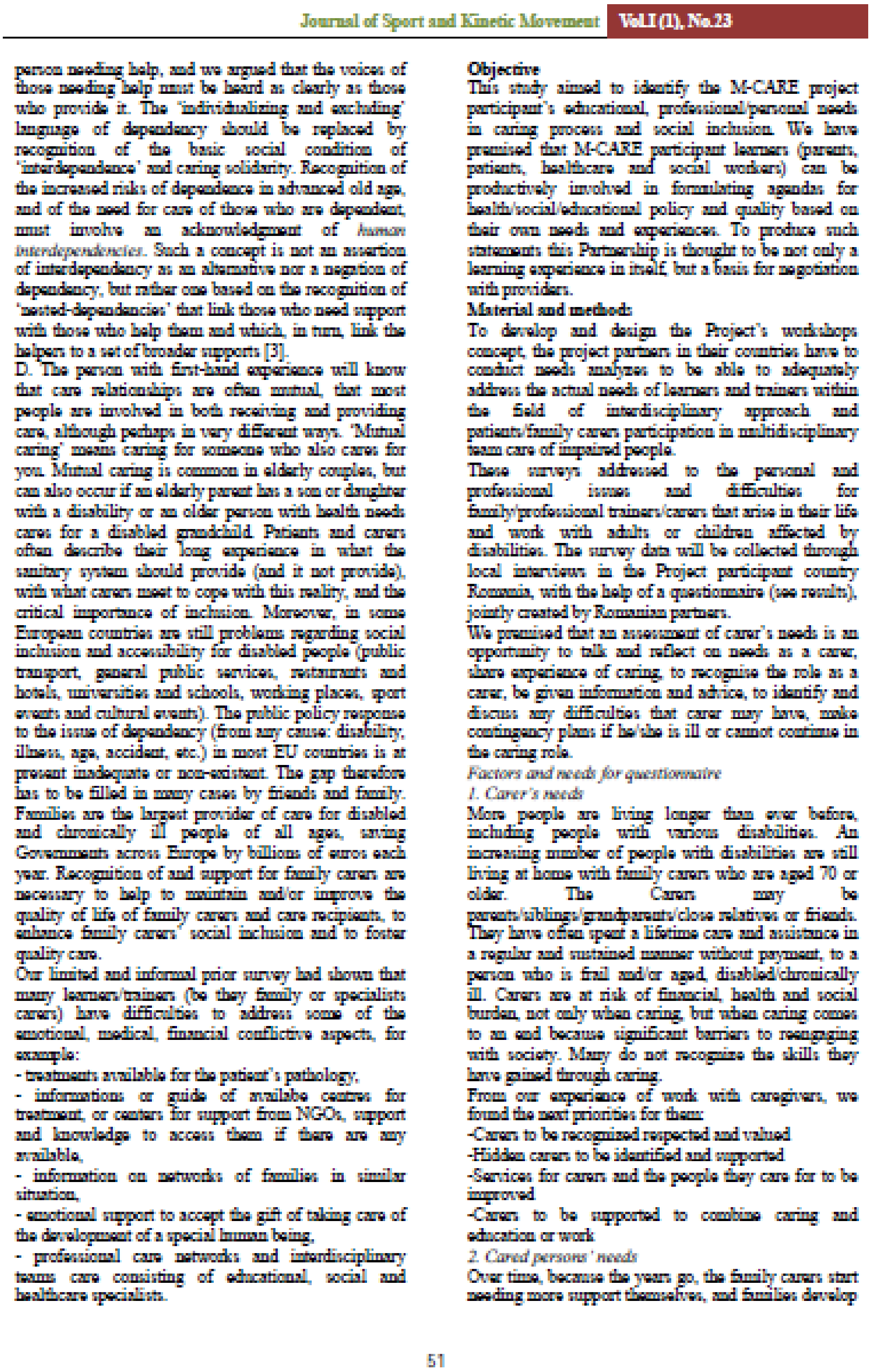
The focus of this paper is on the role of demand and motivation, through participants's needs analyzes, in adult education and formulating agendas for health, social, educational policy and quality based on their own needs and experiences. The research has been carried out within the framework of the *Grundtvig Learning Partnership* project "M-CARE – Mutual caring–from knowledge to action". The project basic premise is that mutual caring understanding and transfer (routines and ways of coping developed by families through both the caring person and affected person are looking after each other) can provide the basis for an innovative learning approach, in which 'mutual care' and 'interdependency' should underlie educational topics on disability issues. The main objective of this project is to understand/define, develop and promote good practices in supporting families to plan for a future where a person with chronically ill/disabilities is providing care to their elderly carers through the concept of mutual caring. The introduction and practical application of these new concepts (but universally applicable) into care process can lead to innovative strategies that are sustainable and cost neutral.

The concept behind the *mutual care approach* focuses on the interpersonal care-dependent person or carer-patient dynamics where there is a mutual exchange of care between the carer and care recipient, in contrast to the conventional approach to carer-care recipient relationships where care is provided by the carer to the cared person. The *project basic premise is that mutual caring knowledge and transfer* (routines and ways of coping developed by families through both the caring person and the affected person are looking after each other) can provide the basis for an innovative learning approach in a joined up work between those in need and disability/social/healthcare services, and for development of the capacity of local/national authorities to respond to the needs of these groups of people. There is an abundance of projects and initiatives that target persons with disability and their carers. However challenges and barriers still exist. We have identified some impediments to effective knowledge, care services, education and real inclusion:

A. Most of these initiatives are still constructed, largely subconsciously, within the framework of the dominant world views and paradigms; thereby –to some extent– perpetuating of these ways of being and doing must to be changed. For too long our tendency has been to study and measure problems and to take curative action, instead of examining the underlying causes, imagining how they can be avoided and embarking on the necessary integrated programs of personal and political change.

B. Neither *"care"* nor *"dependency"* has simple, uncontested meanings. Both refer to a range of social phenomena that involve diverse characteristics that extend from physical activities, through the social relationships among individuals and groups, to the mental states or dispositions involved in caring about someone or being dependent [1]. Research and theoretical critiques have suggested that 'care' does not denote a narrow set of activities or tasks, undertaken without the active engagement of the supposed beneficiary. Instead, 'care' is a complex concept that (with the exception of forms of self-care) cannot be undertaken by one person alone; it is a daily reality, a set of practices and ways of going about support. Recent studies of care suggest that qualities of reciprocal dependence underlie much of what is termed 'care'. Rather than being a unidirectional activity in which an active care-giver does something to a passive and dependent recipient, these accounts suggest that 'care' is best understood as the product or outcome of the relationship between two or more people [2].

C. The concept of 'dependency' too often connotes negative 'burdens' and deficiencies on the part of the



person needing help, and we argued that the voices of those needing help must be heard as clearly as those who provide it. The 'individualizing and excluding' language of dependency should be replaced by recognition of the basic social condition of 'interdependence' and caring solidarity. Recognition of the increased risks of dependence in advanced old age, and of the need for care of those who are dependent, must involve an acknowledgment of *human interdependencies*. Such a concept is not an assertion of interdependency as an alternative nor a negation of dependency, but rather one based on the recognition of 'nested-dependencies' that link those who need support with those who help them and which, in turn, link the helpers to a set of broader supports [3].

D. The person with first-hand experience will know that care relationships are often mutual, that most people are involved in both receiving and providing care, although perhaps in very different ways. 'Mutual caring' means caring for someone who also cares for you. Mutual caring is common in elderly couples, but can also occur if an elderly parent has a son or daughter with a disability or an older person with health needs cares for a disabled grandchild. Patients and carers often describe their long experience in what the sanitary system should provide (and it not provide), with what carers meet to cope with this reality, and the critical importance of inclusion. Moreover, in some European countries are still problems regarding social inclusion and accessibility for disabled people (public transport, general public services, restaurants and hotels, universities and schools, working places, sport events and cultural events). The public policy response to the issue of dependency (from any cause: disability, illness, age, accident, etc.) in most EU countries is at present inadequate or non-existent. The gap therefore has to be filled in many cases by friends and family. Families are the largest provider of care for disabled and chronically ill people of all ages, saving Governments across Europe by billions of euros each year. Recognition of and support for family carers are necessary to help to maintain and/or improve the quality of life of family carers and care recipients, to enhance family carers' social inclusion and to foster quality care.

Our limited and informal prior survey had shown that many learners/trainers (be they family or specialists carers) have difficulties to address some of the emotional, medical, financial conflictive aspects, for example:

- treatments available for the patient's pathology,
- informations or guide of availabe centres for treatment, or centers for support from NGOs, support and knowledge to access them if there are any available,
- information on networks of families in similar situation,
- emotional support to accept the gift of taking care of the development of a special human being,
- professional care networks and interdisciplinary teams care consisting of educational, social and healthcare specialists.

Objective

This study aimed to identify the M-CARE project participant's educational, professional/personal needs in caring process and social inclusion. We have premised that M-CARE participant learners (parents, patients, healthcare and social workers) can be productively involved in formulating agendas for health/social/educational policy and quality based on their own needs and experiences. To produce such statements this Partnership is thought to be not only a learning experience in itself, but a basis for negotiation with providers.

Material and methods

To develop and design the Project's workshops concept, the project partners in their countries have to conduct needs analyzes to be able to adequately address the actual needs of learners and trainers within the field of interdisciplinary approach and patients/family carers participation in multidisciplinary team care of impaired people.

These surveys addressed to the personal and professional issues and difficulties for family/professional trainers/carers that arise in their life and work with adults or children affected by disabilities. The survey data will be collected through local interviews in the Project participant country Romania, with the help of a questionnaire (see results), jointly created by Romanian partners.

We premised that an assessment of carer's needs is an opportunity to talk and reflect on needs as a carer, share experience of caring, to recognise the role as a carer, be given information and advice, to identify and discuss any difficulties that carer may have, make contingency plans if he/she is ill or cannot continue in the caring role.

Factors and needs for questionnaire

1. Carer's needs

More people are living longer than ever before, including people with various disabilities. An increasing number of people with disabilities are still living at home with family carers who are aged 70 or older. The Carers may be parents/siblings/grandparents/close relatives or friends. They have often spent a lifetime care and assistance in a regular and sustained manner without payment, to a person who is frail and/or aged, disabled/chronically ill. Carers are at risk of financial, health and social burden, not only when caring, but when caring comes to an end because significant barriers to reengaging with society. Many do not recognise the skills they have gained through caring.

From our experience of work with caregivers, we found the next priorities for them:

-Carers to be recognized respected and valued
-Hidden carers to be identified and supported
-Services for carers and the people they care for to be improved
-Carers to be supported to combine caring and education or work

2. Cared persons' needs

Over time, because the years go, the family carers start needing more support themselves, and families develop routines and ways of coping, that mean that both the older person and the person with disabilities, whether mental or physical, are looking after each other. Often the cared persons are providing regular care for their ageing relatives (shopping, cleaning, cooking, accompanying each other on days out, providing emotional support). Therefore, without each other's support, neither person would be able to remain living independently within their local community. Thus they reach to meet the above mentioned 'nested-dependencies' that characterise 'exchange-based reciprocity', which is the basis of mutual care.

But even though the mutual caring among families is increasing, often remains hidden. Some of the main dissatisfactions for people with disabilities which are turn into caregivers include:

-not being recognised for their role as a carer

-many do not recognise the skills they have gained through caring

-not being offered many choices about how support is provided or continuing to care

-lack of information that is accessible and easy to understand about rights as a carer, available support health conditions of their elderly relative

-lack of practical support and benefit advice that could make a big difference with shopping, getting to appointments

-isolation and reduced opportunities for breaks from caring and friendship

-fear of being separated if social workers discover the extent of the mutual caring that is happening

These are issues for many carers but are often more of a struggle for persons with disabilities. And when they surmount, they want to feel proud of helping out and returning the care and support that has been provided to them by their parents for so many years.

3. Educational needs

-Redefining the terms 'care' and 'dependency' into 'mutual care' and 'interdependency' is not only an appealing linguistic solution to the difficult dilemmas we have considered, but should underlie educational approaches on disability issues

-Extrapolating, mutuality (simultaneously recognizing similarities in one another's experiences, thinking and feeling/being willing to share them openly, experiencing connectedness, communion and a sense of 'we) could redesign educational systems to enable learning and transformation, rather than by imposing the learning agendas of others

-By recognition that families and unpaid carers constitute the largest care force, they should be considered as key partners and providers not only in the planning/design/delivery of care, but also in professionals' education.

-Professional training for all health and social care staff should include a substantial component which relates to unpaid carers as partners in care, carers' needs and the diversity of the unpaid caring experience; that training should contain carer modules and input from carers and service users.

-Carers and care receivers should be able to access education and training as and when required to support their caring task and help them develop their own skills, knowledge and expertise; these must be maintained and easily accessible to all.

An assessment is not about carer capability to care but it will look at ways in which professionals can best help in the caring role. To understand the caring role and agree how best professionals can offer support, the carer should be asked about:

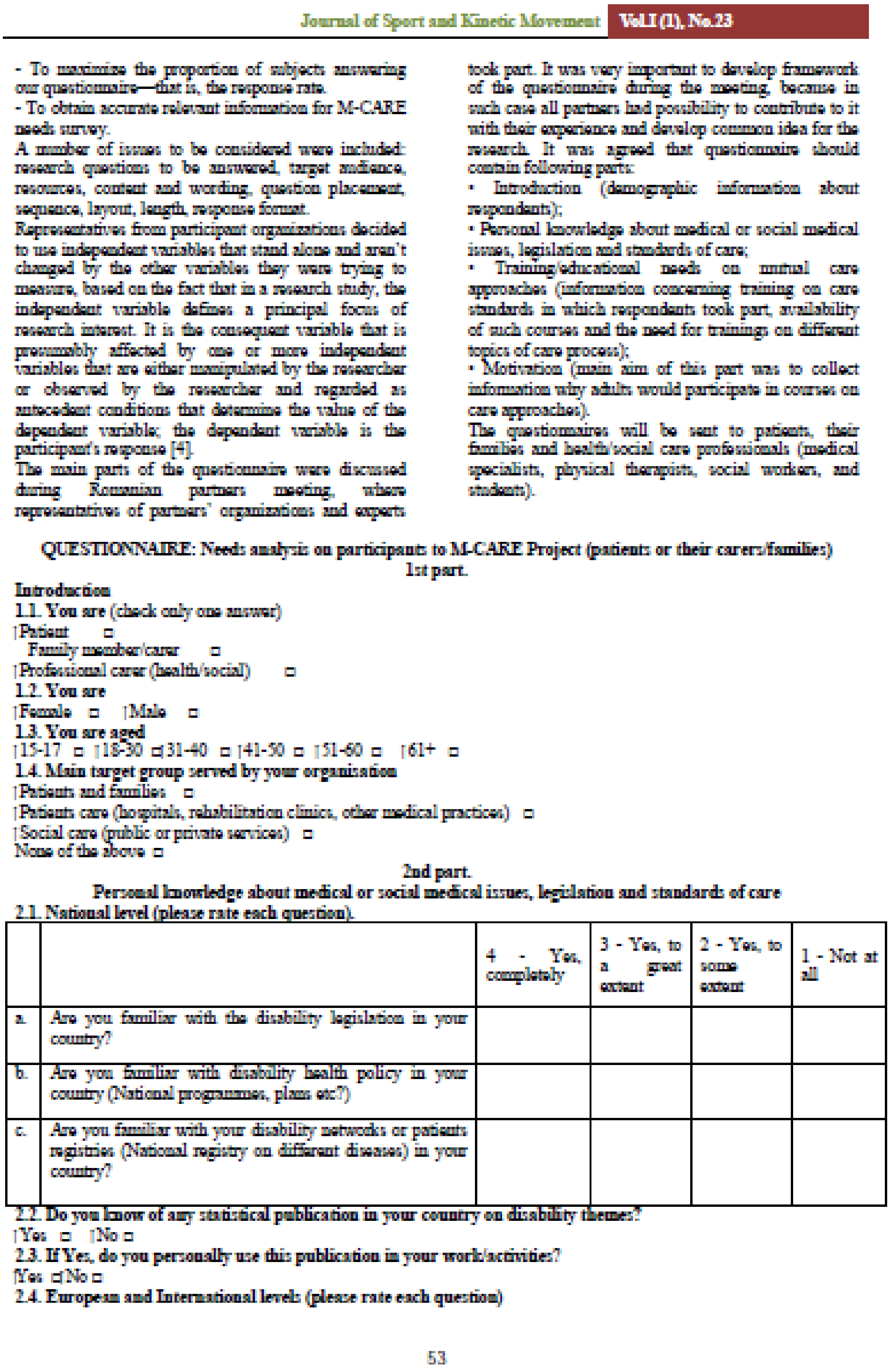
- the caring role – how much time is taken up; do you feel you have a choice to care; which aspects do you find particularly difficult; do you understand the condition of the person you care for?
- about having a break from caring – do you have any leisure time for yourself or time with friends; when did you last have time for yourself?
- emotional and physical health – are you well; are you doing any caring tasks that put you at risk, for example lifting someone; do you get a full night's sleep; are you feeling anxious or stressed?
- relationships – if you are a parent, do your caring responsibilities make parenting harder; how is your relationship with the person you care for?
- caring for home/accommodation – are you finding it difficult to maintain your home and look after the person you care for; do you do all of the housework; would adaptations/ equipment help?
- finances – are they a problem?
- work/education and training – do you want to stay in work or return to work; are you worried that you might have to give up education or training because of your caring role?
- support – what help do you get at the moment – is it enough?
- other responsibilities – what other responsibilities do you have, for example, are you a parent/carer for another person; is balancing these responsibilities causing you difficulties?
- the future – how do you see the future; what is likely to affect your ability to care long term?
- emergencies/alternative arrangements – what would happen to the person you care for if you were to suddenly become ill; do you know who to contact in an emergency? What might signal that you can no longer cope/care?

The recommendations for the design of questionnaire for the assessment and expression of their needs by family/professional carers, are based on the cumulative work of the M-CARE, specifically:

- guiding principles of the learning partnership (these guiding principles have been elaborated and agreed upon by partners in order to give an ethical framework to the partnership);
- findings from national surveys to identify obstacles to family/specialists -assessment of their needs;
- the characteristics identified during the examination of best practice examples collected at national level;
- recommendations on training provision to be made for family carers and professionals to help family carers assess and express their needs.

Results

The objectives in designing M-CARE needs questionnaire have been:



- To maximize the proportion of subjects answering our questionnaire—that is, the response rate.
- To obtain accurate relevant information for M-CARE needs survey.

A number of issues to be considered were included: research questions to be answered, target audience, resources, content and wording, question placement, sequence, layout, length, response format.

Representatives from participant organizations decided to use independent variables that stand alone and aren't changed by the other variables they were trying to measure, based on the fact that in a research study, the independent variable defines a principal focus of research interest. It is the consequent variable that is presumably affected by one or more independent variables that are either manipulated by the researcher or observed by the researcher and regarded as antecedent conditions that determine the value of the dependent variable; the dependent variable is the participant's response [4].

The main parts of the questionnaire were discussed during Romanian partners meeting, where representatives of partners' organizations and experts took part. It was very important to develop framework of the questionnaire during the meeting, because in such case all partners had possibility to contribute to it with their experience and develop common idea for the research. It was agreed that questionnaire should contain following parts:

- Introduction (demographic information about respondents);
- Personal knowledge about medical or social medical issues, legislation and standards of care;
- Training/educational needs on mutual care approaches (information concerning training on care standards in which respondents took part, availability of such courses and the need for trainings on different topics of care process);
- Motivation (main aim of this part was to collect information why adults would participate in courses on care approaches).

The questionnaires will be sent to patients, their families and health/social care professionals (medical specialists, physical therapists, social workers, and students).

QUESTIONNAIRE: Needs analysis on participants to M-CARE Project (patients or their carers/families)

1st part.

Introduction

1.1. You are (check only one answer)

|Patient ☐
Family member/carer ☐
|Professional carer (health/social) ☐

1.2. You are

|Female ☐ |Male ☐

1.3. You are aged

|15-17 ☐ |18-30 ☐|31-40 ☐ |41-50 ☐ |51-60 ☐ |61+ ☐

1.4. Main target group served by your organisation

|Patients and families ☐
|Patients care (hospitals, rehabilitation clinics, other medical practices) ☐
|Social care (public or private services) ☐
None of the above ☐

2nd part.

Personal knowledge about medical or social medical issues, legislation and standards of care

2.1. National level (please rate each question).

		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the disability legislation in your country?				
b.	Are you familiar with disability health policy in your country (National programmes, plans etc?)				
c.	Are you familiar with your disability networks or patients registries (National registry on different diseases) in your country?				

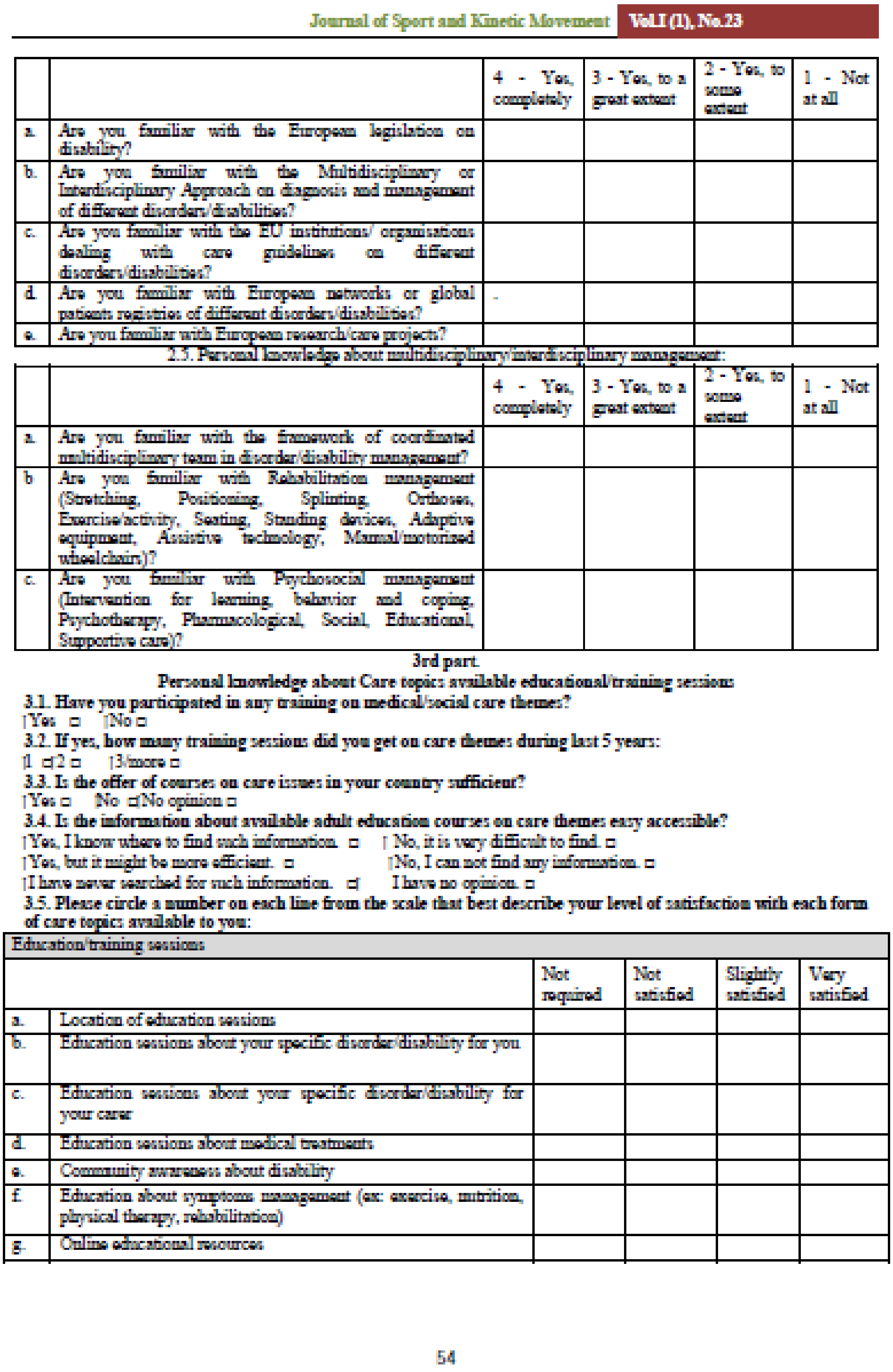
2.2. Do you know of any statistical publication in your country on disability themes?

|Yes ☐ |No ☐

2.3. If Yes, do you personally use this publication in your work/activities?

|Yes ☐|No ☐

2.4. European and International levels (please rate each question)



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		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the European legislation on disability?				
b.	Are you familiar with the Multidisciplinary or Interdisciplinary Approach on diagnosis and management of different disorders/disabilities?				
c.	Are you familiar with the EU institutions/ organisations dealing with care guidelines on different disorders/disabilities?				
d.	Are you familiar with European networks or global patients registries of different disorders/disabilities?	.			
e.	Are you familiar with European research/care projects?				

2.5. Personal knowledge about multidisciplinary/interdisciplinary management:

		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the framework of coordinated multidisciplinary team in disorder/disability management?				
b	Are you familiar with Rehabilitation management (Stretching, Positioning, Splinting, Orthoses, Exercise/activity, Seating, Standing devices, Adaptive equipment, Assistive technology, Manual/motorized wheelchairs)?				
c.	Are you familiar with Psychosocial management (Intervention for learning, behavior and coping, Psychotherapy, Pharmacological, Social, Educational, Supportive care)?				

3rd part.

Personal knowledge about Care topics available educational/training sessions

3.1. Have you participated in any training on medical/social care themes?

Yes ☐ No ☐

3.2. If yes, how many training sessions did you get on care themes during last 5 years:

1 ☐ 2 ☐ 3/more ☐

3.3. Is the offer of courses on care issues in your country sufficient?

Yes ☐ No ☐ No opinion ☐

3.4. Is the information about available adult education courses on care themes easy accessible?

Yes, I know where to find such information. ☐ No, it is very difficult to find. ☐
Yes, but it might be more efficient. ☐ No, I can not find any information. ☐
I have never searched for such information. ☐ I have no opinion. ☐

3.5. Please circle a number on each line from the scale that best describe your level of satisfaction with each form of care topics available to you:

Education/training sessions					
		Not required	Not satisfied	Slightly satisfied	Very satisfied
a.	Location of education sessions				
b.	Education sessions about your specific disorder/disability for you				
c.	Education sessions about your specific disorder/disability for your carer				
d.	Education sessions about medical treatments				
e.	Community awareness about disability				
f.	Education about symptoms management (ex: exercise, nutrition, physical therapy, rehabilitation)				
g.	Online educational resources				

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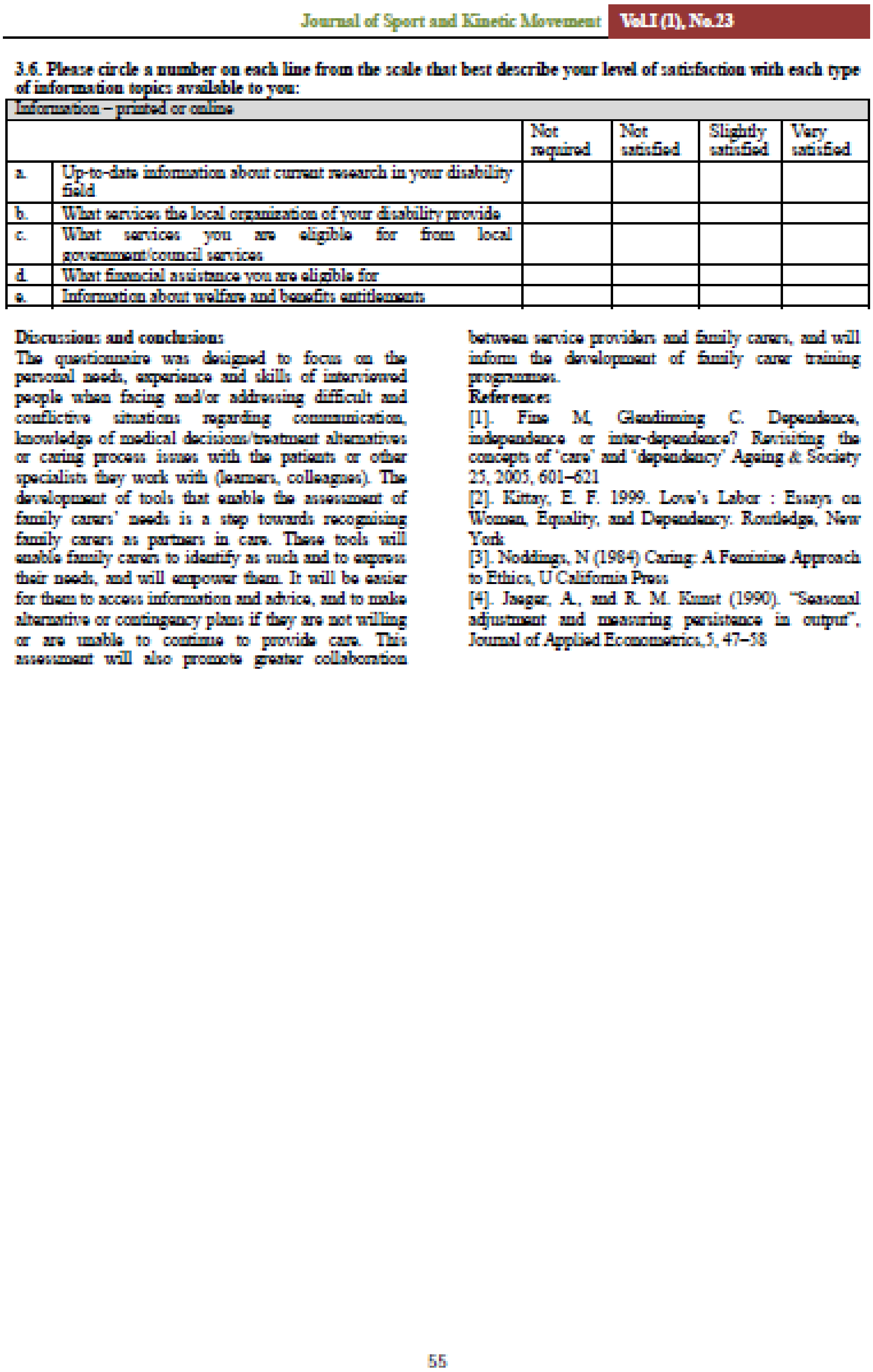

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3.6. Please circle a number on each line from the scale that best describe your level of satisfaction with each type of information topics available to you:

Information – printed or online					
		Not required	Not satisfied	Slightly satisfied	Very satisfied
a.	Up-to-date information about current research in your disability field				
b.	What services the local organization of your disability provide				
c.	What services you are eligible for from local government/council services				
d.	What financial assistance you are eligible for				
e.	Information about welfare and benefits entitlements				

Discussions and conclusions

The questionnaire was designed to focus on the personal needs, experience and skills of interviewed people when facing and/or addressing difficult and conflictive situations regarding communication, knowledge of medical decisions/treatment alternatives or caring process issues with the patients or other specialists they work with (learners, colleagues). The development of tools that enable the assessment of family carers' needs is a step towards recognising family carers as partners in care. These tools will enable family carers to identify as such and to express their needs, and will empower them. It will be easier for them to access information and advice, and to make alternative or contingency plans if they are not willing or are unable to continue to provide care. This assessment will also promote greater collaboration between service providers and family carers, and will inform the development of family carer training programmes.

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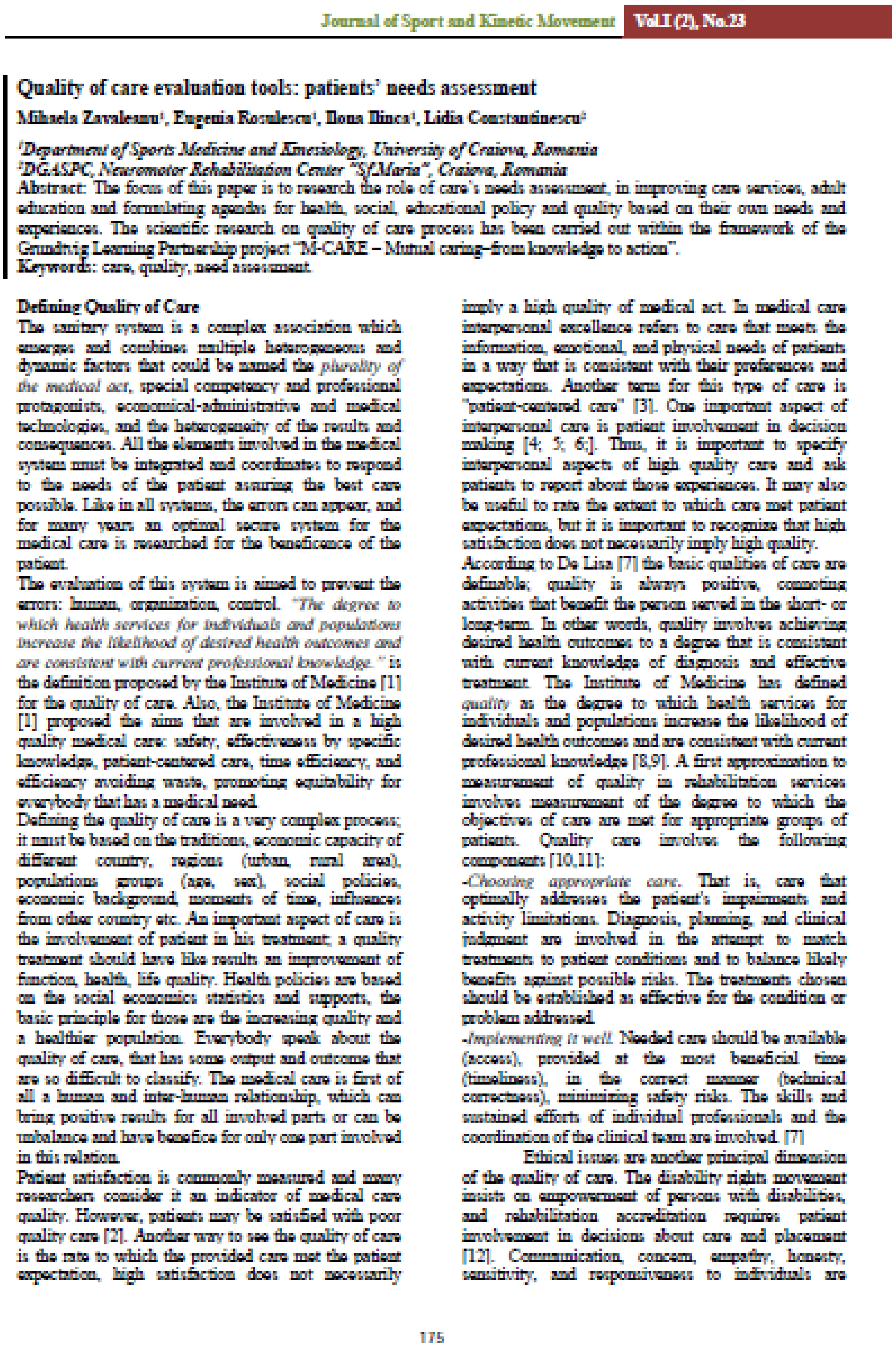

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Quality of care evaluation tools: patients' needs assessment

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Abstract: The focus of this paper is to research the role of care's needs assessment, in improving care services, adult education and formulating agendas for health, social, educational policy and quality based on their own needs and experiences. The scientific research on quality of care process has been carried out within the framework of the Grundtvig Learning Partnership project "M-CARE – Mutual caring–from knowledge to action".

Keywords: care, quality, need assessment.

Defining Quality of Care

The sanitary system is a complex association which emerges and combines multiple heterogeneous and dynamic factors that could be named the *plurality of the medical act*, special competency and professional protagonists, economical-administrative and medical technologies, and the heterogeneity of the results and consequences. All the elements involved in the medical system must be integrated and coordinates to respond to the needs of the patient assuring the best care possible. Like in all systems, the errors can appear, and for many years an optimal secure system for the medical care is researched for the beneficence of the patient.

The evaluation of this system is aimed to prevent the errors: human, organization, control. *"The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."* is the definition proposed by the Institute of Medicine [1] for the quality of care. Also, the Institute of Medicine [1] proposed the aims that are involved in a high quality medical care: safety, effectiveness by specific knowledge, patient-centered care, time efficiency, and efficiency avoiding waste, promoting equitability for everybody that has a medical need.

Defining the quality of care is a very complex process; it must be based on the traditions, economic capacity of different country, regions (urban, rural area), populations groups (age, sex), social policies, economic background, moments of time, influences from other country etc. An important aspect of care is the involvement of patient in his treatment; a quality treatment should have like results an improvement of function, health, life quality. Health policies are based on the social economics statistics and supports, the basic principle for those are the increasing quality and a healthier population. Everybody speak about the quality of care, that has some output and outcome that are so difficult to classify. The medical care is first of all a human and inter-human relationship, which can bring positive results for all involved parts or can be unbalance and have benefice for only one part involved in this relation.

Patient satisfaction is commonly measured and many researchers consider it an indicator of medical care quality. However, patients may be satisfied with poor quality care [2]. Another way to see the quality of care is the rate to which the provided care met the patient expectation, high satisfaction does not necessarily imply a high quality of medical act. In medical care interpersonal excellence refers to care that meets the information, emotional, and physical needs of patients in a way that is consistent with their preferences and expectations. Another term for this type of care is "patient-centered care" [3]. One important aspect of interpersonal care is patient involvement in decision making [4; 5; 6;]. Thus, it is important to specify interpersonal aspects of high quality care and ask patients to report about those experiences. It may also be useful to rate the extent to which care met patient expectations, but it is important to recognize that high satisfaction does not necessarily imply high quality.

According to De Lisa [7] the basic qualities of care are definable; quality is always positive, connoting activities that benefit the person served in the short- or long-term. In other words, quality involves achieving desired health outcomes to a degree that is consistent with current knowledge of diagnosis and effective treatment. The Institute of Medicine has defined *quality* as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge [8,9]. A first approximation to measurement of quality in rehabilitation services involves measurement of the degree to which the objectives of care are met for appropriate groups of patients. Quality care involves the following components [10,11]:

-*Choosing appropriate care.* That is, care that optimally addresses the patient's impairments and activity limitations. Diagnosis, planning, and clinical judgment are involved in the attempt to match treatments to patient conditions and to balance likely benefits against possible risks. The treatments chosen should be established as effective for the condition or problem addressed.

-*Implementing it well.* Needed care should be available (access), provided at the most beneficial time (timeliness), in the correct manner (technical correctness), minimizing safety risks. The skills and sustained efforts of individual professionals and the coordination of the clinical team are involved. [7]

Ethical issues are another principal dimension of the quality of care. The disability rights movement insists on empowerment of persons with disabilities, and rehabilitation accreditation requires patient involvement in decisions about care and placement [12]. Communication, concern, empathy, honesty, sensitivity, and responsiveness to individuals are

important [13]. *Quality health care* is based on provision of effective care. Specification of optimally effective care is difficult in a field as complex and broad as rehabilitation, but the evidence basis for rehabilitation is growing and increasingly defined [7]. Explication, implementation, and improvement of guidelines for care are basic to efforts to assure and improve the routine core quality of care. [14].The guidelines for care are quality care criteria for the evaluation of quality. The scientific literature has also been used to develop evidence-based practice guidelines and to evaluate both the appropriateness of use of procedures and the quality of inpatient care received by patients with multiple conditions [15].

Definition of need

Clinical aspects of illness can be assessed using standardized needs assessment instruments that measure symptom-based outcomes. Assessment of the impact of an illness on an individual's quality of life, social functioning, and role functioning and service satisfaction requires patient-based measures [16], these underpinning the discussion on assessment schedules and their uses.

Medical Research Council's definition of Needs for Care Assessment according to Brewin [17], comprises:

-*Need is present when:* (a) a patient's functioning (social disablement) falls below or threatens to fall below some minimum specified level; and (b) this is owing to a remediable, or potentially remediable, cause.

-*A need* (as defined above) is met when it has attracted some at least partly effective item of care, and when no other items of care of greater potential effectiveness exist.

-*A need* (as defined above) is unmet when it has attracted only partly effective or no item of care and when other items of care of greater potential effectiveness exist.

All those implied in the process of care need to know many information about the assessment possibilities available and about the evaluation of results after offered care. Those evaluations can be the base for an informed decision to start an efficient care plan. Assessment and evaluation – essentially the translation of the results of assessment into quantifiable or numerical form – are becoming ubiquitous in healthcare [16], thus policy makers assume that assessment and evaluation will improve the clinical and cost-effectiveness of mental health services.

Concept of need

In 1972, Bradshaw's [18] framework the concept of need in four different ways of thinking:

Normative need is defined by reference to 'appropriate' standards or required levels of services or outcomes determined by expert opinion. Individuals or groups falling short of these standards are defined as being in need. But normative need is by no means absolute, as Bradshaw observes, normative need 'may be tainted with a charge of paternalism'. Moreover, experts may have different and possibly conflicting standards.

Comparative need is determined by comparing the resources or services available in one area — be it a community, a population group or individual — with those that exist in another. A community, population group or person is considered to be in 'need' if they have say more health or social problems, or less access to services, than others. The main problem with the concept of comparative need are its two underlying assumptions — first, that similarities exist between the areas and second, that the appropriate response to the 'problem' is to align service levels. This need not hold true, for example, when both areas experience chronic shortages for a particular service. *Felt need* has a subjective element and is defined in terms of what individuals state their needs to be or say they want. It can be defined easily by asking current or potential service users what they wish to have. But felt need by itself is generally considered to be an inadequate measure of 'real need'. For example felt need can be inflated by users' own high expectations. *Expressed need* is defined in terms of the services people use. It is based on what can be inferred about a person or a community by observing their use of services (or waiting lists for services). A community or person who uses a lot of services is assumed to have high needs. While a community or person who does not, is assumed to have low needs. But expressed need is influenced by the availability of services — a person cannot use or put their name down on a waiting list for a service that is not offered.

Assessment of care quality and care needs

A large number of different assessment tools exist in the area of medical care, and their content varies. No generally accepted classification of care yet exists on which to base such tools that none adequately address all of the domains which are significant for disability care patients. As Owen et al. [19] noted, '*Assessment is a valuable intervention in its own right, and is not just the entry point into service provision*'. The assessment process can provide an opportunity for individuals to articulate their care and support needs, identify issues that need to be addressed in any personal plan, and be used to collect data. Assessments would be person-centred, taking account of people's unique circumstances. The need assessment has important functions [16]:

-To define health and social care needs at an individual level

-To help care planning (need should predict intervention)

-To monitor change in social care needs over time as a measure of the effectiveness of care planning for the individual

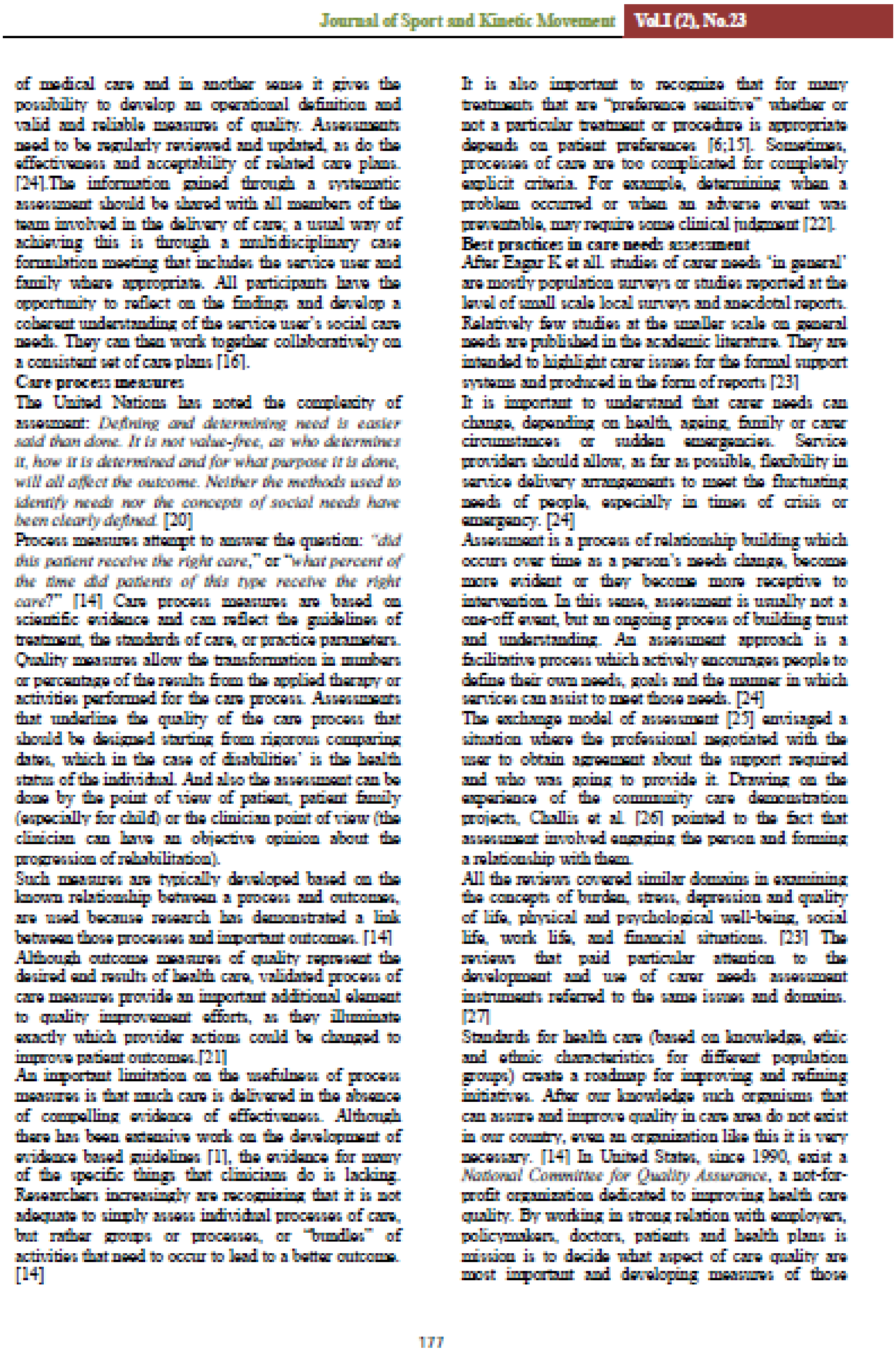
-To define health and social care needs at a population level

-To track changes in social care needs within services over time

-To support research and evaluation

-To guide service development and planning

Also the base of medical practice is the research that can give some sense to the idea of quality



of medical care and in another sense it gives the possibility to develop an operational definition and valid and reliable measures of quality. Assessments need to be regularly reviewed and updated, as do the effectiveness and acceptability of related care plans. [24].The information gained through a systematic assessment should be shared with all members of the team involved in the delivery of care; a usual way of achieving this is through a multidisciplinary case formulation meeting that includes the service user and family where appropriate. All participants have the opportunity to reflect on the findings and develop a coherent understanding of the service user's social care needs. They can then work together collaboratively on a consistent set of care plans [16].

Care process measures

The United Nations has noted the complexity of assessment: *Defining and determining need is easier said than done. It is not value-free, as who determines it, how it is determined and for what purpose it is done, will all affect the outcome. Neither the methods used to identify needs nor the concepts of social needs have been clearly defined.* [20]

Process measures attempt to answer the question: *"did this patient receive the right care,"* or "*what percent of the time did patients of this type receive the right care?*" [14] Care process measures are based on scientific evidence and can reflect the guidelines of treatment, the standards of care, or practice parameters. Quality measures allow the transformation in numbers or percentage of the results from the applied therapy or activities performed for the care process. Assessments that underline the quality of the care process that should be designed starting from rigorous comparing dates, which in the case of disabilities' is the health status of the individual. And also the assessment can be done by the point of view of patient, patient family (especially for child) or the clinician point of view (the clinician can have an objective opinion about the progression of rehabilitation).

Such measures are typically developed based on the known relationship between a process and outcomes, are used because research has demonstrated a link between those processes and important outcomes. [14]

Although outcome measures of quality represent the desired end results of health care, validated process of care measures provide an important additional element to quality improvement efforts, as they illuminate exactly which provider actions could be changed to improve patient outcomes.[21]

An important limitation on the usefulness of process measures is that much care is delivered in the absence of compelling evidence of effectiveness. Although there has been extensive work on the development of evidence based guidelines [1], the evidence for many of the specific things that clinicians do is lacking. Researchers increasingly are recognizing that it is not adequate to simply assess individual processes of care, but rather groups or processes, or "bundles" of activities that need to occur to lead to a better outcome. [14]

It is also important to recognize that for many treatments that are "preference sensitive" whether or not a particular treatment or procedure is appropriate depends on patient preferences [6;15]. Sometimes, processes of care are too complicated for completely explicit criteria. For example, determining when a problem occurred or when an adverse event was preventable, may require some clinical judgment [22].

Best practices in care needs assessment

After Eagar K et all. studies of carer needs 'in general' are mostly population surveys or studies reported at the level of small scale local surveys and anecdotal reports. Relatively few studies at the smaller scale on general needs are published in the academic literature. They are intended to highlight carer issues for the formal support systems and produced in the form of reports [23]

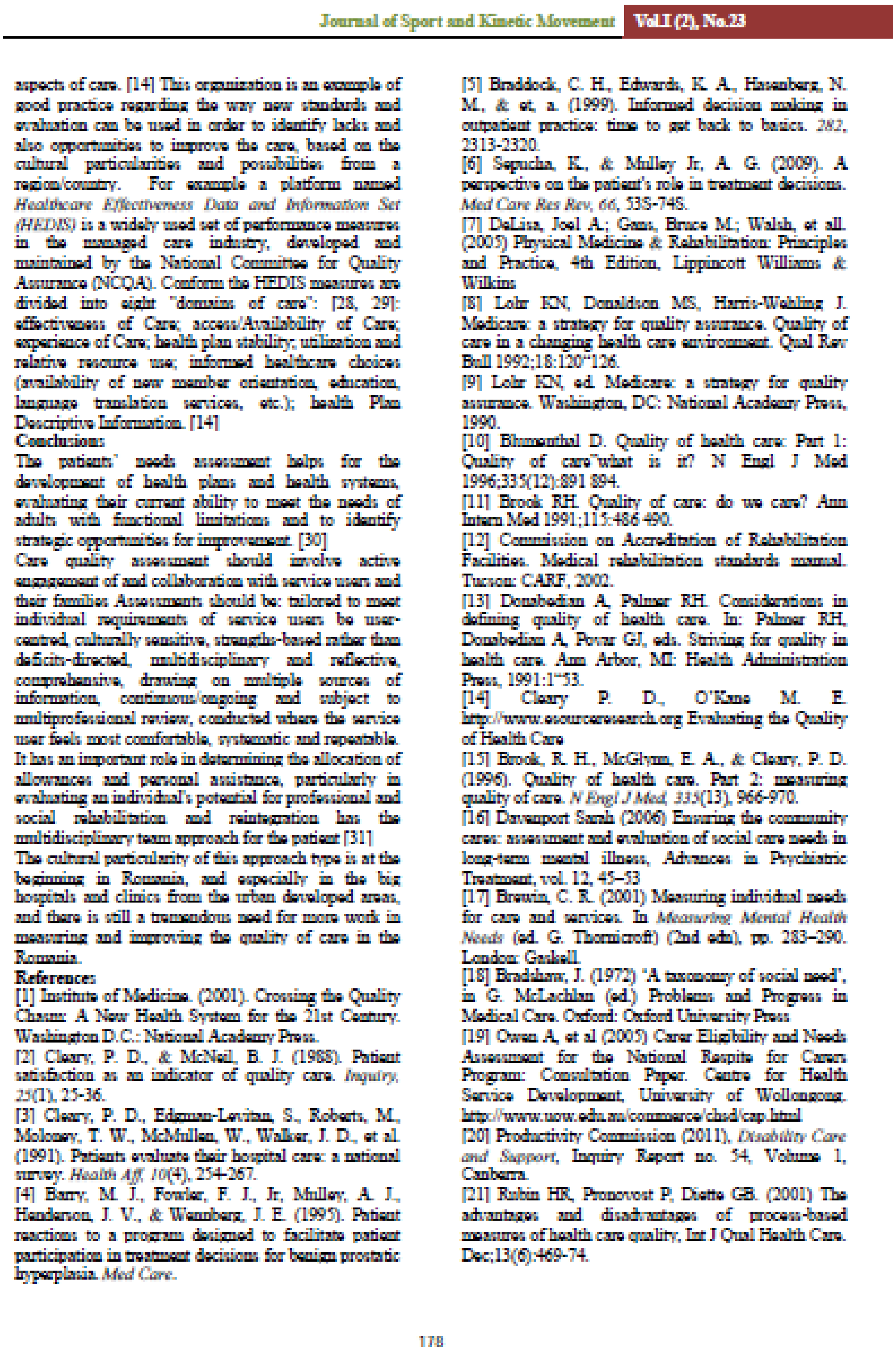
It is important to understand that carer needs can change, depending on health, ageing, family or carer circumstances or sudden emergencies. Service providers should allow, as far as possible, flexibility in service delivery arrangements to meet the fluctuating needs of people, especially in times of crisis or emergency. [24]

Assessment is a process of relationship building which occurs over time as a person's needs change, become more evident or they become more receptive to intervention. In this sense, assessment is usually not a one-off event, but an ongoing process of building trust and understanding. An assessment approach is a facilitative process which actively encourages people to define their own needs, goals and the manner in which services can assist to meet those needs. [24]

The exchange model of assessment [25] envisaged a situation where the professional negotiated with the user to obtain agreement about the support required and who was going to provide it. Drawing on the experience of the community care demonstration projects, Challis et al. [26] pointed to the fact that assessment involved engaging the person and forming a relationship with them.

All the reviews covered similar domains in examining the concepts of burden, stress, depression and quality of life, physical and psychological well-being, social life, work life, and financial situations. [23] The reviews that paid particular attention to the development and use of carer needs assessment instruments referred to the same issues and domains. [27]

Standards for health care (based on knowledge, ethic and ethnic characteristics for different population groups) create a roadmap for improving and refining initiatives. After our knowledge such organisms that can assure and improve quality in care area do not exist in our country, even an organization like this it is very necessary. [14] In United States, since 1990, exist a *National Committee for Quality Assurance*, a not-for-profit organization dedicated to improving health care quality. By working in strong relation with employers, policymakers, doctors, patients and health plans is mission is to decide what aspect of care quality are most important and developing measures of those



aspects of care. [14] This organization is an example of good practice regarding the way new standards and evaluation can be used in order to identify lacks and also opportunities to improve the care, based on the cultural particularities and possibilities from a region/country. For example a platform named *Healthcare Effectiveness Data and Information Set (HEDIS)* is a widely used set of performance measures in the managed care industry, developed and maintained by the National Committee for Quality Assurance (NCQA). Conform the HEDIS measures are divided into eight "domains of care": [28, 29]: effectiveness of Care; access/Availability of Care; experience of Care; health plan stability; utilization and relative resource use; informed healthcare choices (availability of new member orientation, education, language translation services, etc.); health Plan Descriptive Information. [14]

Conclusions

The patients' needs assessment helps for the development of health plans and health systems, evaluating their current ability to meet the needs of adults with functional limitations and to identify strategic opportunities for improvement. [30]

Care quality assessment should involve active engagement of and collaboration with service users and their families Assessments should be: tailored to meet individual requirements of service users be user-centred, culturally sensitive, strengths-based rather than deficits-directed, multidisciplinary and reflective, comprehensive, drawing on multiple sources of information, continuous/ongoing and subject to multiprofessional review, conducted where the service user feels most comfortable, systematic and repeatable.

It has an important role in determining the allocation of allowances and personal assistance, particularly in evaluating an individual's potential for professional and social rehabilitation and reintegration has the multidisciplinary team approach for the patient [31]

The cultural particularity of this approach type is at the beginning in Romania, and especially in the big hospitals and clinics from the urban developed areas, and there is still a tremendous need for more work in measuring and improving the quality of care in the Romania.

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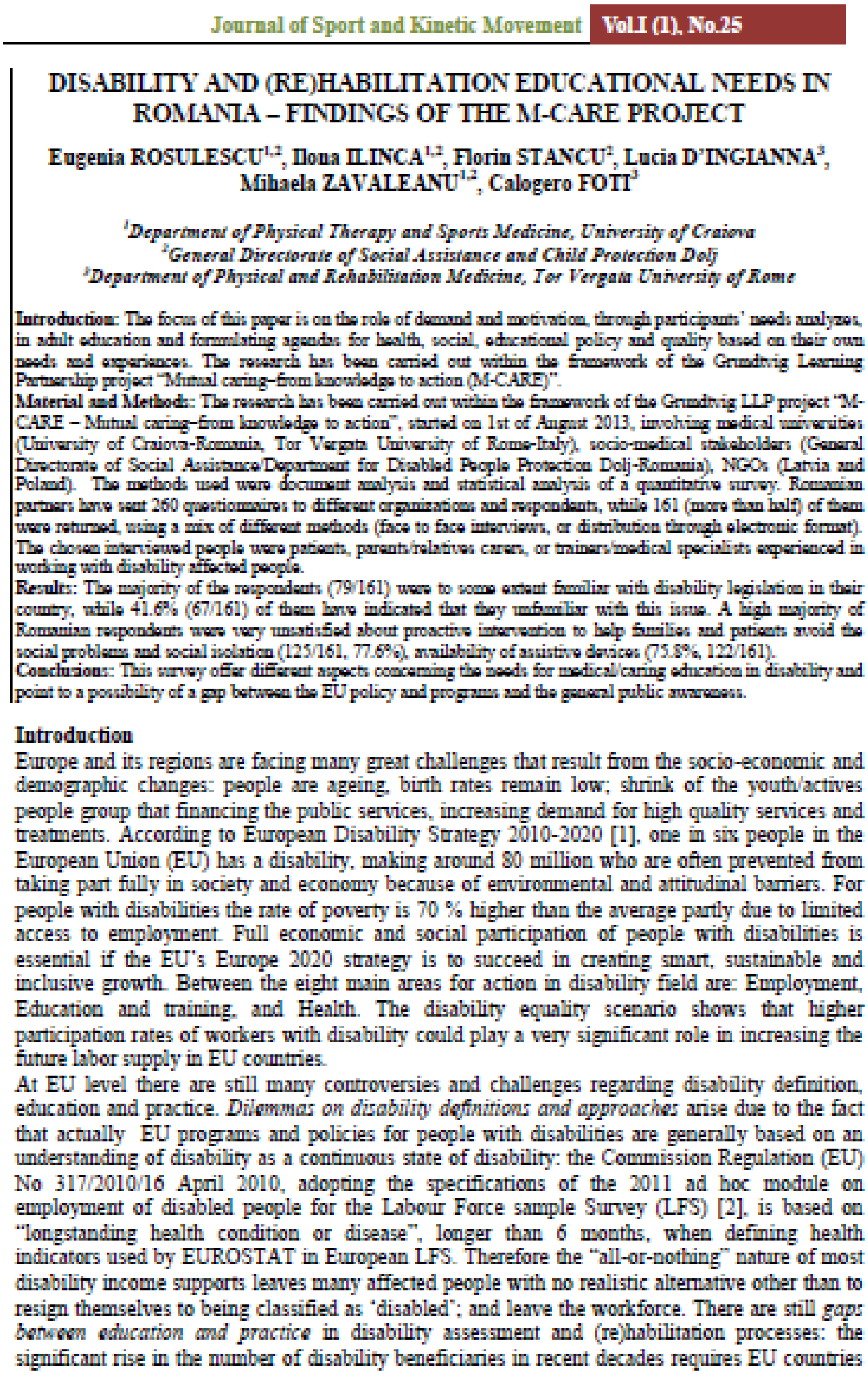

Journal of Sport and Kinetic Movement Vol.I (1), No.25

DISABILITY AND (RE)HABILITATION EDUCATIONAL NEEDS IN ROMANIA – FINDINGS OF THE M-CARE PROJECT

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Introduction: The focus of this paper is on the role of demand and motivation, through participants' needs analyses, in adult education and formulating agendas for health, social, educational policy and quality based on their own needs and experiences. The research has been carried out within the framework of the Grundtvig Learning Partnership project "Mutual caring–from knowledge to action (M-CARE)".

Material and Methods: The research has been carried out within the framework of the Grundtvig LLP project "M-CARE – Mutual caring–from knowledge to action", started on 1st of August 2013, involving medical universities (University of Craiova-Romania, Tor Vergata University of Rome-Italy), socio-medical stakeholders (General Directorate of Social Assistance/Department for Disabled People Protection Dolj-Romania), NGOs (Latvia and Poland). The methods used were document analysis and statistical analysis of a quantitative survey. Romanian partners have sent 260 questionnaires to different organizations and respondents, while 161 (more than half) of them were returned, using a mix of different methods (face to face interviews, or distribution through electronic format). The chosen interviewed people were patients, parents/relatives carers, or trainers/medical specialists experienced in working with disability affected people.

Results: The majority of the respondents (79/161) were to some extent familiar with disability legislation in their country, while 41.6% (67/161) of them have indicated that they unfamiliar with this issue. A high majority of Romanian respondents were very unsatisfied about proactive intervention to help families and patients avoid the social problems and social isolation (125/161, 77.6%), availability of assistive devices (75.8%, 122/161).

Conclusions: This survey offer different aspects concerning the needs for medical/caring education in disability and point to a possibility of a gap between the EU policy and programs and the general public awareness.

Introduction

Europe and its regions are facing many great challenges that result from the socio-economic and demographic changes: people are ageing, birth rates remain low; shrink of the youth/actives people group that financing the public services, increasing demand for high quality services and treatments. According to European Disability Strategy 2010-2020 [1], one in six people in the European Union (EU) has a disability, making around 80 million who are often prevented from taking part fully in society and economy because of environmental and attitudinal barriers. For people with disabilities the rate of poverty is 70 % higher than the average partly due to limited access to employment. Full economic and social participation of people with disabilities is essential if the EU's Europe 2020 strategy is to succeed in creating smart, sustainable and inclusive growth. Between the eight main areas for action in disability field are: Employment, Education and training, and Health. The disability equality scenario shows that higher participation rates of workers with disability could play a very significant role in increasing the future labor supply in EU countries.

At EU level there are still many controversies and challenges regarding disability definition, education and practice. *Dilemmas on disability definitions and approaches* arise due to the fact that actually EU programs and policies for people with disabilities are generally based on an understanding of disability as a continuous state of disability: the Commission Regulation (EU) No 317/2010/16 April 2010, adopting the specifications of the 2011 ad hoc module on employment of disabled people for the Labour Force sample Survey (LFS) [2], is based on "longstanding health condition or disease", longer than 6 months, when defining health indicators used by EUROSTAT in European LFS. Therefore the "all-or-nothing" nature of most disability income supports leaves many affected people with no realistic alternative other than to resign themselves to being classified as 'disabled'; and leave the workforce. There are still *gaps between education and practice* in disability assessment and (re)habilitation processes: the significant rise in the number of disability beneficiaries in recent decades requires EU countries to rethink their approach to addressing working-age disability; there was and still is too much focus on a diagnosis of loss of physical and/or mental functioning, as assessed by medical practitioners with no or limited expertise in (re)habilitation. Practician's competencies in the area of disability affect the fairness and validity of assessments and interventions. Concerning the *health and social care*, the medical diagnosis is often not effective as the full means of determining the type of supports that might help the individual. New approaches are need to move away from providing supports based on a diagnosis or medical criteria to providing supports based on the impact of disability. Differences in the impact of a disability between one individual and another may be the result of the nature and severity of the health condition, their life circumstances, and the barriers and supports that are part of their lives.

Besides the previously mentioned issues, more people are living longer than ever before, including people with various disabilities. An increasing number of people with disabilities are still living at home with family carers who are aged 70 or older. The carers may be parents, siblings, grandparents, close relatives or friends. They have often spent a lifetime care and assistance in a regular and sustained manner without payment, to a person who is frail and/or aged, disabled/chronically ill. Carers are at risk of financial, health and social burden, not only when caring, but when caring comes to an end because significant barriers to reengaging with society. Many do not recognize the skills they have gained through caring. From our experience of work with caregivers, we found the next priorities and needs for them: to be recognized, respected and valued; hidden carers to be identified and supported; the improvement of services for carers and the people they care for; to be supported to combine caring and education or work.

Therefore, the reasons mentioned above actuated and provided and us the motivation to create the M-CARE Learning Partnership involving the exchange of knowledge, information, staff and learners across Europe. This Learning Partnership is focused on motivation and demand, on participants' needs analysis, setting objectives which are participant-led, introducing new concepts, but universally applicable, which can lead to innovative strategies that are sustainable and cost neutral. Through the development of mutualistic relationships in education and healthcare services our ability to share life/ or learned experiences will increase, for a better collaboration in envisioning and creating a more humane and integrated society.

The M-CARE basic premise was that mutual caring understanding and transfer (routines and ways of coping developed by families through both the caring person and affected person are looking after each other) can provide the basis for an innovative learning approach, in which 'mutual care' and 'interdependency' should underlie educational topics on disability issues. The main objective of this project was to understand and define, develop and promote good practices in supporting families to plan for a future where a person with chronically ill/disabilities is providing care to their elderly carers through the concept of mutual caring. The introduction and practical application of these new concepts (but universally applicable) into care process can lead to innovative strategies that are sustainable and cost neutral.

The concept behind the "mutual care approach" focuses on the interpersonal care-dependent person or carer-patient dynamics where there is a mutual exchange of care between the carer and care recipient, in contrast to the conventional approach to carer-care recipient relationships where care is provided by the carer to the cared person. There is an abundance of projects and initiatives that target persons with disability and their caregivers, as resulted from our research activities unrolled during the 2 years life of M-CARE. However challenges and barriers still exist. We have identified many impediments to effective knowledge, care services, education and real inclusion: the majority of these initiatives are still constructed, largely subconsciously, within the framework of the dominant world views and paradigms; neither "care" nor "dependency" has simple, uncontested meanings; the "individualizing and excluding" language of dependency should be replaced by recognition of the basic social condition of "interdependence"" and caring solidarity [3,4].

Our limited and informal prior surveys had shown that many learners/trainers (be they family or specialists caregivers) have difficulties to address some of the emotional, medical, financial conflictive aspects, such as: treatments available for the patient's pathology, information or guides of available centers for treatment, or centers for support from NGOs, support and knowledge to access them if there are any available, information on networks of families in similar situation, emotional support to accept the gift of taking care of the development of a special human being, professional care networks and interdisciplinary teams care consisting of educational, social and healthcare specialists.

Our study objectives were to identify the M-CARE project participant's educational, professional/personal needs in caring process and social inclusion, by taken the assumption that M-CARE participant learners (parents, patients, healthcare specialists, social workers) can be productively involved in formulating agendas for health/social/educational policy and quality based on their own needs and experiences.

Material and Methods

The research has been carried out within the framework of the Grundtvig LLP project ""M-CARE – Mutual caring–from knowledge to action", started on 1st of August 2013, involving medical universities (University of Craiova-Romania / UCV, Tor Vergata University of Rome-Italy), socio-medical stakeholders (General Directorate of Social Assistance and Children Protection, Department for Disabled People Protection Dolj-Romania / DGASPC), NGOs (Latvia and Poland). To develop and design the Project's workshops concept, the project partners in their countries had to conduct needs analyzes to be able to adequately address the actual needs of learners and trainers within the field of interdisciplinary approach and patients/family carers participation in multidisciplinary team care of impaired people.

These surveys addressed to the personal and professional issues and difficulties for individuals, families, professional trainers or carers that arise in their life and work with adults or children affected by disabilities. The surveys data have been collected through local interviews, in the Project participant country Romania, with the help of a questionnaire [3] jointly created by Romanian partners. The objectives in designing M-CARE needs questionnaire have been: to maximize the proportion of subjects answering our questionnaire—that is, the response rate; to obtain accurate relevant information for M-CARE needs survey.

A number of issues to be considered were included: research questions to be answered, target audience, resources, content and wording, question placement, sequence, layout, length, response format. Representatives from participant organizations decided to use independent variables that stand alone and aren't changed by the other variables they were trying to measure, based on the fact that in a research study, the independent variable defines a principal focus of research interest. It is the consequent variable that is presumably affected by one or more independent variables that are either manipulated by the researcher or observed by the researcher and regarded as antecedent conditions that determine the value of the dependent variable; the dependent variable is the participant's response [5].

The main parts of the questionnaire were discussed during Romanian partners meeting, where representatives of partners' organizations and experts took part. It was very important to develop framework of the questionnaire during the meeting, because in such case all partners had possibility to contribute to it with their experience and develop common idea for the research. It was agreed that questionnaire should contain following parts: (1) Introduction (demographic information about respondents); (2) Personal knowledge about medical or social medical issues, legislation and standards of care; (3) Training/educational needs on mutual care approaches - information concerning training on care standards in which respondents took part, availability of such courses and the need for trainings on different topics of care process (see the Annex).

The methods used were document analysis and statistical analysis of a quantitative survey. Romanian partners have sent questionnaires to different respondents, using a mix of methods (face to face interviews, or distribution through electronic format), but the most effective was the distribution of the questionnaires during some special events (seminars, workshops, conferences, etc.) or sending to the people or organizations with which project partners were cooperating. The chosen interviewed people were patients, parents/relatives caregivers, or trainers/medical specialists experienced in working with disability affected people.

Results

More than 260 questionnaires were sent to different organizations and respondents, while 161 (more than half, 61.92%) of them were returned. Questioning was taking place during 9 months: from May 2014 to January 2015. Partners were responsible for collection of the questionnaires from respondents and imputing their answers to the Excel table. The methods used were document analysis and statistical analysis of a quantitative survey.

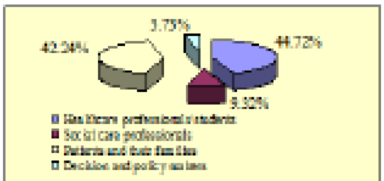


Fig 1. Typology of respondents

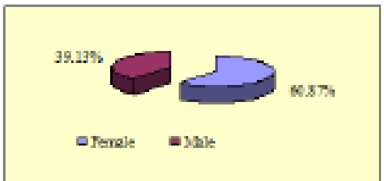


Fig. 2. Distribution by gender

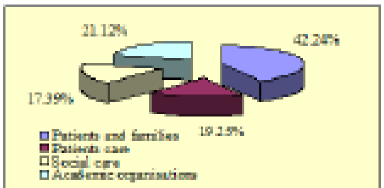


Fig. 3. Target groups served by the organisations

Personal knowledge about medical or social medical issues, legislation and standards of care (SOC)

The next set of questions was focusing on respondents' knowledge of different care issues. The majority of the respondents (79/161) only to some extent are familiar with disability legislation in their country, while 41.6% (67/161) of them have indicated that they are completely unfamiliar with this issue. Regarding disability health policy, 109/161 (67.7%) respondents declared that are not informed about it.

The same tendencies have been noticed in answers to the question if respondents are familiar with disability networks or patients registries in their country: a small percent of the respondents knows very little about these topics (17.4%, 28/161), and 99 (61.5%) of the respondents were completely ignorant with these information channels.

Table 1. Being familiar with disability care issues at National level

		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the disability legislation in your country?	**3**	**12**	**79**	**67**
b.	Are you familiar with disability health policy in your country (National programmes, plans etc?)	**7**	**11**	**34**	**109**
c.	Are you familiar with your disability networks or patients registries (National registry on different diseases) in your country?	**10**	**24**	**28**	**99**

Almost the same situation has been be noticed speaking about the interdisciplinary or multidisciplinary approach on diagnosis and management of disability.

It should be noticed, that even 52.8 percent (85/161) of Romanians have no idea about the framework of coordinated multidisciplinary team in disorder/disability management, 64/161 were to some extent familiarwith this topic.

A high majority of Romanian respondents were uninformed about psychosocial management and proactive intervention to help families and patients to avoid the social problems and social isolation (125/161, 77.6%), and the use or availability of assistive devices (75.8%, 122/161).

Table 2. Being familiar with disability multidisciplinary/interdisciplinary management

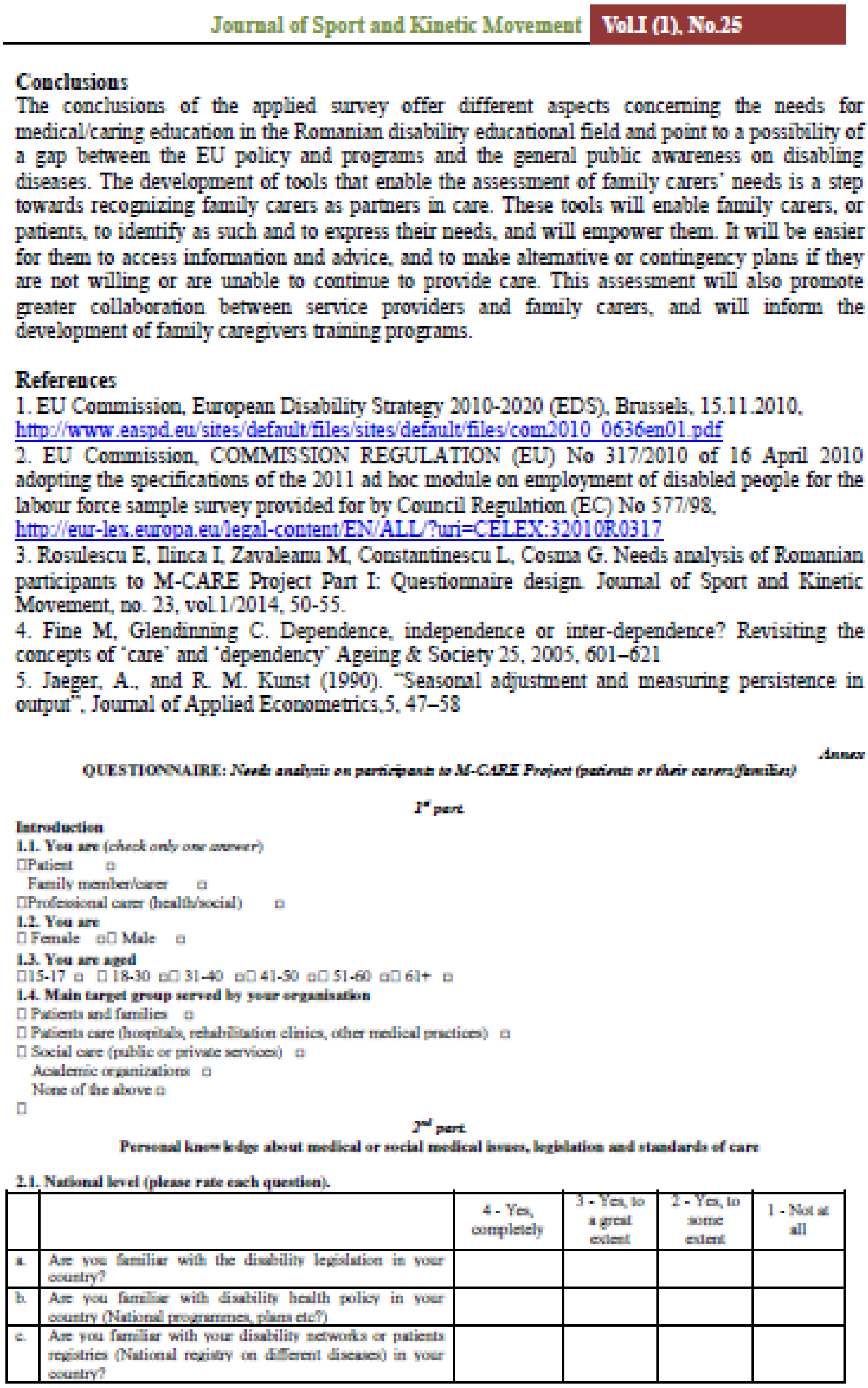
		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the framework of coordinated multidisciplinary team in disorder/disability management?	5	7	64	85
b	Are you familiar with Rehabilitation management (Stretching, Positioning, Splinting, Orthoses, Exercise/activity, Seating, Standing devices, Adaptive equipment, Assistive technology, Manual/motorized wheelchairs)?	6	24	122	9
c.	Are you familiar with Psychosocial management (Intervention for learning, behavior and coping, Psychotherapy, Pharmacological, Social, Educational, Supportive care)?	5	12	19	125

Discussions

The questionnaire was designed to focus on the personal needs, experience and skills of interviewed people when facing and/or addressing difficult and conflictive situations regarding communication, knowledge of medical decisions/treatment alternatives or caring process issues with the patients or other specialists they work with (learners, colleagues). The development of tools that enable the assessment of family carers' needs is a step towards recognizing family as partners in care. These tools will enable family caregivers to identify as such and to express their needs, and will empower them. It will be easier for them to access information and advice, and to make alternative or contingency plans if they are not willing or are unable to continue to provide care.

One limitation of our study may be sample size. The consultation document points out that our M-CARE Grundtvig Project wants to serve as a platform for all stakeholders in the disability care field to participate on our joint objectives.

By this research work we found that there are still unmet education and training needs: (1) For people with disabilities: the need of empowering people living with disability (or disadvantaged population group) in terms of knowledge on their rights, policy, inclusion and full participation in society, adaptability and employability skills, raising the knowledge on their diseases, career planning, employment and self-employment abilities, and how to access information/services/technology and employment resources, so that they can enjoy their full rights and benefit fully from participating in society and in EU economy; (2) For researchers and education/training providers: the need of exploring a plurality of disability definitions to design, disseminate and translate a multidisciplinary knowledge framework on disability (re)habilitation, to ensure a raised relevance of this subject in professionals' training and disability policy's coherence, and to enhances individual potential and equip graduates with the knowledge and multidisciplinary transferable competences; (3) For health and social professional caregivers (medical practitioners, nurses, physical therapists, social workers, psychologists ..): the need of continuing education in assessing persons with disabilities, accommodations, evolving technology, and laws governing disability issues.



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Conclusions

The conclusions of the applied survey offer different aspects concerning the needs for medical/caring education in the Romanian disability educational field and point to a possibility of a gap between the EU policy and programs and the general public awareness on disabling diseases. The development of tools that enable the assessment of family carers' needs is a step towards recognizing family carers as partners in care. These tools will enable family carers, or patients, to identify as such and to express their needs, and will empower them. It will be easier for them to access information and advice, and to make alternative or contingency plans if they are not willing or are unable to continue to provide care. This assessment will also promote greater collaboration between service providers and family carers, and will inform the development of family caregivers training programs.

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Annex

QUESTIONNAIRE: ***Needs analysis on participants to M-CARE Project (patients or their carers/families)***

1st part

Introduction

1.1. You are *(check only one answer)*
☐Patient ☐
Family member/carer ☐
☐Professional carer (health/social) ☐

1.2. You are
☐ Female ☐☐ Male ☐

1.3. You are aged
☐15-17 ☐ ☐ 18-30 ☐☐ 31-40 ☐☐ 41-50 ☐☐ 51-60 ☐☐ 61+ ☐

1.4. Main target group served by your organisation
☐ Patients and families ☐
☐ Patients care (hospitals, rehabilitation clinics, other medical practices) ☐
☐ Social care (public or private services) ☐
Academic organizations ☐
None of the above ☐
☐

2nd part

Personal knowledge about medical or social medical issues, legislation and standards of care

2.1. National level (please rate each question).

		4 - Yes, completely	3 - Yes, to a great extent	2 - Yes, to some extent	1 - Not at all
a.	Are you familiar with the disability legislation in your country?				
b.	Are you familiar with disability health policy in your country (National programmes, plans etc?)				
c.	Are you familiar with your disability networks or patients registries (National registry on different diseases) in your country?				

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