 doi:10.20944/preprints201808.0224.v1

Narrative Review

Aging and Disability:

The Need of A Bridge To Promote Wellbeing, Quality Of Life And Participation

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Abstract: In the last decades there has been a progressive aging of the population, known as "demographic revolution" or "demographic transition". As a consequence of the worldwide progressive aging of population and of the increasing of general life expectancy, the relationship between aging and disability became a very important one and received a huge interest in research for its consequences on participation, inclusion and quality of life of ageing people and for its consequences on socio-sanitary organizations. The aim of this paper is to analyze this relationship and to discuss consequences on participation, inclusion and quality of life of ageing people, according to recent conceptual models of disability and active ageing. According to previous papers this relationship could be considered in two ways: ageing with disability (which refers to people living with long-term effects of disabling conditions acquired from birth to middle age) and disability with ageing (which refers to people which disabling conditions acquired later or age-related conditions), but newer papers proposed a convergence of these two approaches, taking into account the similarities and the differences between the two ways.

Keywords: disability, ageing, health, disablement, wellbeing, functioning, participation, inclusion, oldest olds, genetics, environmental variables, lifestyles, World Health Organization

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1. Introduction

In the last decades there has been a phenomenon of progressive aging of the population, known as "demographic revolution" or "demographic transition". As a consequence of the worldwide progressive aging of population and of the increasing of general life expectancy, the relationship between aging and disability has become a very important one for its consequences on participation, inclusion and quality of life of ageing people and for its consequences on socio-sanitary organizations [1-5]. In 2017, about 18% of worldwide population is 60 years-old and over, in Europe there are about 25% of people 60 years-old and older and in the North of America the 22% of the population is 60 years-old and older. According to different estimates, in 2080 about 30% of the population in Europe will be 65 years-old and older. According to Eurostat Studies (2016), Italy is

one of the "oldest country" in Europe, with the biggest number of oldest olds (65 years old and over) and with the smallest number of children (0-14 years old)[1].

As a consequence of the worldwide progressive aging of population and the increasing of general life expectancy, the relationship between aging and disability became a very important one and received a huge interest in research. As ageing is a complex phenomenon, related to genetics, constitutional variables, life styles and environmental variable, the focus on any intervention in this field is to control disease, age-related disorders and negative variables and promote well-being. During the human life, there are different phases of development: in the first phases of life there is a progressive increasing of functioning during (from infancy to adolescence), there is a sort of plateau during adult life and then there is a reduction of functioning in ageing. The speediness and the quantity and quality of this reduction is related to genetic variables (about 25%), but most of all it is related to lifestyles and environmental variables [5-7]. A progressive reduction of functioning (related to genetic, to constitutional variables and to lifestyles), together with negative environmental factors, could lead to functional limitations and disability.

In this paper we will describe the relationship between aging and disability according to two different point of view: thanks to the increasing of the quality of socio-sanitary services and sanitary services, there is an increasing of life expectancy for people with disability, so they can age with previous health disabling conditions; the progressive ageing of population is also related to a sort of physiologic reduction of functioning in ageing, and also the increasing of age-related health conditions that could have, so some people could become people with disability only during his/her ageing process. The first point of view is named "ageing with disability" and the second is named "disability with ageing". In this paper we will discuss these two approaches to the relationship between ageing and disability and, then, we will discuss a third newer approach that proposes a convergence between the first two, taking into account the similarities and the differences between the two previous described approaches.

2. Methods

A Narrative review of the literature on ageing and disability was undertaken. Search was based on the following electronic databases: PubMed/Medline (1987-2015), Ovid/PsychINFO (1987–2015). A combination of the following keywords was used: (1) ageing or aging (2) disability or disablement. Only published studies in English were included. Retrieved abstracts were scanned for relevance, and the full paper was retrieved. The reference list of the retrieved reviews was examined, too, to identify potential additional studies. Two authors assessed all the retrieved articles for inclusion, on the basis of their titles and abstracts. Two more authors independently assessed the selected records again and inspected the full article. In the following paragraphs a narrative description of the papers included in the narrative review. According to the methodology of a narrative review, the following paragraphs will describe only in a qualitative manner the findings of the papers included.

2.1. Disability according to ICF and other recent conceptual models of disability

First of all, we have to declare that nowadays there is an international agreement in the use of a dynamic vision of disability, the one proposed by International Classification of Functioning, disability and Health of the World Health Organization [8] and other conceptual models of disability

[1] http://ec.europa.eu/eurostat/statistics-explained/index.php/Main_Page

and approved by the United Convention of the Rights of the People with Disabilities [9-11]. According to this vision, Disability is the consequence of the relationship of the person, with his/her health conditions, and the environment [9-11]. However, in the studies considered in the narrative review, there could be also different visions of disability, related to the approach or the approaches chosen by single author or single study. So in the following paragraph the dynamic vision of disability is not the only one we will quote, but we will also quote the approach or the approaches proposed by each study we considered.

3. The World Report on disability by the World Health Organization

In 2011, World Health Organization and the World Bank published a report on worldwide data on disability [12]. Even in this report, disability is considered according to the dynamic vision just described: disablement is a dynamic, complex and multidimensional process, and it is the consequence of the interaction between the person with his/her health condition, and the environment [12]. The main consequences of dynamic vision of disability is a difficulty in the estimation of the prevalence of disability. However the report estimates that about 15,3% of people were people with disability in 2004 and about 15% of people in 2010. About 2-4% of this people with disability has severe functional limitations. The report describes countries differences (a higher prevalence in lower income countries), gender differences (a higher prevalence in women) and age differences (a higher prevalence in older people) [12].

In a recent European study from 17 European countries based on SHARE Project, Jerez-Roig and colleagues (2017) reported that about 16% of community-dwelling subjects ageing 65 and over are people with disability, and about 18,2% of Italian community-dwelling subjects ageing 65 and over are people with disability. They described disability as at least one functional limitation in basic activities of daily living. The authors also described health conditions related to the functional limitations: they showed a central role of not-communicable diseases (like hypertension for 55,3%, Cardiovascular disorders 27,6% and diabetes 24,5%) [13].

4. Conceptual models of ageing and the semantic of ageing

During the second part of Twentieth Century worldwide there have been also an important process of conceptualization also on active ageing, successful ageing, healthy ageing, positive ageing, developmental and dynamic ageing [1-5, 14-16]. Elsewhere, we described these conceptualization [4-5]. For the aim of this paper, the main convergence of all the models is that the focus is always on the wellbeing and the quality of life of ageing people. According to the seminal work of Rowe and Kahn [1-2] there is also an attention to the distinction between three different kinds of ageing: usual ageing, active ageing and pathological ageing [1-5,7]. From this point of view, the aim of each kind of intervention is to prevent pathological ageing, to reduce the risk of age-related health conditions and their consequences, to promote active and health ageing and to prevent the changing from usual to pathological ageing. Well-being and good quality of life are to be considered central aims for each ageing person, and for the aim of this paper, also for people with disability. If we consider for example the conceptual model proposed by World Health Organization [14-16], the meaning of healthy and active ageing is not being without disorders or without disease, but it refers to wellbeing from a biopsychosocial point of view, so it refers to wellbeing and quality of life, even in the presence of a disease or a disorder. These topics are strictly subjective and individually- and

 doi:10.20944/preprints201808.0224.v1

sociocultural-defined. WHO defines active ageing as a process of optimization of opportunity related to health, participation and security, so these are the keywords related to active ageing. And it is important to note that there is not only individual responsibility but also social responsibility in this field and the aim is to promote and increase quality of life of ageing people. From the Conceptualization of the WHO, the main features and the key elements that make a good quality of life, and then an active ageing, is the recognition of the centrality of the person who is ageing and the possibility to maintain, along all the phases of life, autonomy (that means maintain control and decision making in the different domains of our self life), independency (the ability to choose and do, also with help, activities of daily living) and a good quality of life [4-5, 14-16]. Based on our studies in community where there is a high prevalence of longevity people, we developed another conceptual model of ageing, named "dynamic and developmental ageing". Elsewhere, we described this model [4-5]. For the aim of this paper, the main features of this approach are: the role of psychological variables (like meaning of life, spirituality, coping strategies in front of negative life events, ability to forget negative events and to overcome negative situations, the capacity to maintain control over different domains of life, autonomy in daily life activities), the role of lifestyles (longevity people continue to make an "ecological physical activity" daily, like gardening, doing housekeeping and housework, walking and doing other physical activities), the role of eating attitudes and diet (a specific kind of Mediterranean diet with high level of fruits, vegetables, milks and other products and the centrality of bread and related products and little quantity of wine), no solution of continuity in role and job (no retirement, there is no stop of the role in the society), no solution of continuity in the possibility to decide for our own life, the role of family and social network (relatives, and friends), the possibility to maintain independency and autonomy [4-5].

5. The Encyclopedia of Geropsychology

In the Encyclopedia of Geropsychology, Barlow and Walker described the relationship between aging and disability and they discussed that the increasing of life expectancy of people has, as a main consequence, a wide variability of health conditions related to disability [17]. They also described epidemiological differences of this health conditions in different countries in the world: in lower income countries, as a consequence of lower availability of drugs and socio-sanitary services, some kinds of health conditions could have more negative effects on people's life. The authors also describe the role of physiological and biological changes during ageing in the reduction of autonomy (see for example the reduction of sensory acuity or other changes related to bone density, muscle mass, and circulatory and respiratory systems). Barlow and Walker described also risk factors that could increase the effects of these physiological and biological changes on functioning of ageing people: life styles variables, environmental variables and constitutional variables [17]. They highlight the role of economic factors (like poverty and social disadvantage) and their effects on daily life. Poverty could have a cumulative effect during life and it could have a increasing effect in the different phases of life. According to the authors, also gender has an important effect: women have a longer life expectancy but the they also have more age –related disorders with a more severe effect on functioning [17]. The effects on activities of daily living and autonomy are another topic considered by the authors: the main aspects are related to mobility (in the external environment, with clear consequences in the use access of socio-sanitary services). Mobility is also related to

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walking and other daily living activities, like using the toilette, taking a bath. All this aspects are strictly related to cognitive abilities (the reduction of mobility can produce a reduction of cognitive abilities), physical domain (the risk of falling and frequent falls) and psychological domain (the fear of falling and the tendency to reduce activities in order to control the fear of falling) [17]. But the authors considered also the consequences in participation and social inclusion of ageing people and the highlighted the positive role of age-friendly environment in the enablement of ageing people and the negative role of ageism in the disablement of ageing people [17].

6. Ageing with disability and Disability with ageing: two different paths?

In 2002, Verbrugge and Li-Shou Yang described two kinds of relationship between aging and disability: the first is named "ageing with disability" and it refers to people who age and who have had some kinds of health conditions since their birth, infancy, childhood or adolescence, or adulthood, the second is named "disability with ageing" and it refers to people who age and develop some kinds of health conditions during ageing (age-related disorders and disease) [18]. With a general increasing of life expectancy for general population and for people with some kinds of health conditions, the two types of relationship between aging and disability tend to converge and there are also a third kind of relationship: some people who have previous health conditions can develop new health conditions during ageing. In their studies, Verbrugge and Li-ShouYang [18] analyzed two samples of U.S. adults with 107.00 and 97.000 aged 65 and over they found that the mean prevalence of disability is about 14.8%. They considered disability the presence of almost a difficulty in doing ADL, almost a difficulty in doing IADL or almost a difficult in doing a PLIM (Physical limitation task, like go on 10 stairs without stop, walking for 250 meters and standing for about 20 minutes). For the child-onset disability (onset before 20 years old) they found the following characteristics: they have a higher number of ADL, IADL or PLIMs impaired, they have a better perception of their health, they have a higher number of sensory impairments. For the Adult-onset disability (onset after 20 years old) the authors found a higher frequency of single woman, a higher socioeconomic level and an higher number of physical impairments. With reference to social participation, in child-onset disability the authors found a higher involvement in job activities and a higher sense of identity and being part of. The reduction of social participation is related to: for child-onset disability is related to be female, the number of chronic disorders, number of impairments in PLIMs and low family income, for adult-onset disability the pattern is similar but with a higher association between the above described variable. The perception of low level of general health is a better predictor of low level of social participation, than the number of ADL or IADL impaired [18]. So, in this paper Verbrugge proposed to distinguish between this two group of people and to consider peculiar characteristic of ageing with disability and disability with ageing [18].

But some years Later, Verbrugge and colleagues proposed another vision in this field [19]. In 2017, in an interesting research on aging with disability in midlife and ageing, they described "Aging with disability" as persistent functional problems for years, or decades, or even one's whole lifetime, with regards both young persons with severe functional problems from birth or acquired in childhood/adolescence but also disability that begins at middle and older ages. Again, they considered disability the persistent presence of almost a difficulty in doing ADL, almost a difficulty in doing IADL or almost a difficult in doing a PLIM (Physical limitation task, like go on 10 stairs

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without stop, walking for 250 meters and standing for about 20 minutes) and they compared 51 years-old and over and 65 years-old and over (two samples of about 32.000 and 24.000 of U.S. adults). They used a complementary approach to identify persons with persistent disability, one based directly on observed data and the other on latent classes. Both approaches show that persistent disability is more common for persons aged 65 and over than aged 51 and over and more common for physical limitations than IADLs and ADLs. They also found that people with persistent disability have social and health disadvantages compared to people with other longitudinal experiences and they proposed to integrate ageing with disability and disability with ageing and to consider the aging with disability an age-free (all ages) rather than age-targeted (children and youths) perspective and they said: *"Whether persistent disability starts early or late in the life course, the consequences for individuals are large and protracted. People face enduring problems in accomplishing goals, they must adapt daily life and attitudes, and they can feel angry or depressed. These are common topics for youth with early-onset disabilities. They are just as germane for midlife and older adults who age with disability. We posit that social and emotional consequences are similar for all age-groups, no matter when persistent disability begins. Specific goals and problems will vary by age, but overarching life issues are the same" (*[19], *pag. 767).* In a similar vein, Monahan and Wolf [20] proposed to consider the continuum of disability in the lifespan and to consider a convergence of the two different approaches, ageing with disability (where the aim is to gain a level of independence despite a longstanding or lifetime disabling condition) and ageing into disability (where there is a loss of previous abilities and autonomy, after a lifetime of not disabling conditions): *" By focusing our attentionon the funding streams and policy initiatives, we seethe divisions more than the convergence of issues. However, bringing the aging and disability perspectives togethermight improve the prospects for creating a research agenda that more accurately captures the essential issues that are faced by adults aging with and into disability" (*[20], *pag S1).*

7. Bridging the gap between ageing with disability and disability with ageing

In 2017, Campbell and Putnam claimed that there is a common tendency to the study of chronic conditions by age group and disability history or diagnosis and this approach has had the effect to limit the understanding of chronic conditions among persons aging with a disability [21]. Aiming to promote a better understanding of chronic conditions, they distinguish three kinds of consequences in people with disability, with differences and convergences according to the age of onset of the first disabling conditions. A first kind of consequences is "disability- related secondary conditions": they can have an increased likelihood of secondary conditions directly or indirectly (any additional physical or mental health conditions that could results from a primary disabling conditions, but are not a specific feature of it). These are similar to those experienced by ageing people in general, but they occur abut 20-25 years sooner, and they are often described as pre-mature, atypical and accelerated ageing. Some examples are: chronic pain and fatigue, bowel or bladder problems, pressure sores or ulcers, respiratory insufficiency, depression, osteoporosis, accelerated arthritis, falls & fractures, new mobility problems, hypertension [21].

A second kind of consequences is "age-related conditions", related to the aging and to the long-term effects exposure to environmental hazards, or to the effects of poor health behaviors. Some examples are: hypertension, high cholesterol, diabetes, osteoarthritis, heart disease, gait and mobility problems, falls, respiratory infections/chronic obstructive pulmonary disease, urinary incontinence, osteoporosis, skin disease, hearing and vision loss, and dementia [21]. A third kind of

 doi:10.20944/preprints201808.0224.v1

consequences is "Multiple Chronic Conditions", the risk to have different kinds of chronic conditions together, in dyads (hypertension and diabetes), or in triads (cholesterol, hypertension and diabetes) [21]. These three kinds of consequences are very closely related one to the other and have clear influences in health, quality of life, daily life, participation for ageing people and social costs and subjective and objective burden for family and relatives [21]. The authors claimed that persons aging with disability and older adults share a set of chronic conditions, both as a disability related secondary conditions and as age-related chronic conditions. Moreover, people with disability could experience also age-related chronic conditions and disability-related secondary conditions. So, the similarity between the two groups are more than the differences and an approach that do not take into account these aspects could have the risk to do not promote health and wellbeing. Aiming to overcome these risks, the authors proposed to close the gap and create a bridge between ageing with disability and disability with ageing (but also between ageing and disability) and to focus attention to health promotion programs aimed to reduce the burden of chronic conditions of people ageing with disability [21]. According to those authors there is a need to develop health promotion interventions for persons with disability with all ages. They claimed that the progressive ageing of population together with an increased longevity experienced also by people living with long-term disabling conditions, combined with the high risk of secondary chronic health conditions, reinforce the importance of recognizing shared and common experiences in people ageing with disabilities and the need to develop most efficient and effective ways of support wellbeing and quality of life of adults ageing with disabilities [21].

9. Discussion

As a consequence of worldwide progressive aging of population, of the increasing of general life expectancy, and of the increasing of people with disability life experience, the number of people growing older with disability is increasing. Ageing is a complex phenomenon, that is the results of two kinds of processes: primary ageing (is a genetically programmed process and it is an uncontrollable and irreversible one, related to the deterioration of physical and biological functions, during different phases of life) and secondary ageing (that could be influenced by some kind of control, related to lifestyle, psychological, and it could be influenced by social and environmental factors) [7]. The role of social and environmental factors in ageing are very well described in different conceptual models on ageing and its relationship with wellbeing and quality of life. In a positive way, social and environmental factors can enable ageing people and optimize the opportunity of health, wellbeing, participation, autonomy and independency; in a negative way, social and environmental factors can disable ageing people and reduce their opportunity of health, wellbeing, participation, autonomy and independency. Also disability is a complex phenomenon, a process where, according to the newer conceptual models in this field, there is a clear role of social and environmental factors in its dynamic [9-11]. Also in disability conceptual models, in a positive way, social and environmental factors can enable people with disability and optimize the opportunity of health, wellbeing, participation, autonomy and independency; in a negative way, social and environmental factors can disable people with disability and reduce their opportunity of health, wellbeing, participation, autonomy and independency. When we consider the relationship between ageing and disability, the complexity is, if possible, even more. But there is also a general tendency to consider ageing and disability only from a medical model, where the role of social and

environmental factors could be neglected. The papers we selected in the narrative review proposed three different approaches in the study of the relationship of ageing and disability and in the last years tend to converge to the need of a bridge of the gap between this two fields and the authors highlight the need of a knowledge of the similarities between people ageing with disability and people with disability that age [17-21]. They also highlight the need of a comprehensive approach both to ageing and disability, from a biopsychological approach, that allows to consider the relationship between the biological aspects of ageing and disability (of ageing, age-related disorders, chronic disorders), the psychological aspects of ageing and disability, and the social aspects of ageing and disability [21].

10. Conclusions

In summary, the study of ageing with disability and disability with ageing has been (and it is now) the focus of a great number of researches. We are aware that it is not a simple field of discussion. The results of the present narrative review highlights the role of different variables in the functioning and the participation of ageing people with disability, regardless of the age of onset of the disabling conditions. From a psychological point of view and according to a biopsychosocial approach, the main aim in this field of study is to guarantee each person to live in each age and age with well-being, dignity: a way to do this it to promote the more inclusive conceptualization on ageing and disability [4-5, 7, 22-24].

Author Contributions: DRPand RP equally contributed to the design of the study, DRP, LG, LP, RP equally contributed to the qualitative analysis of literature, have drafted the paper, have revised the paper and have approved the final manuscript.

Funding: This study is supported by RP's grant from Fondazione di Sardegna and by DRP's personal research grant from University of Cagliari.

Acknowledgments: The Authors wish to thanks all the oldest olds and their families who collaborated to the researches. The Authors also wish to thanks Ing. Andrea Domenico Petretto for English revision.

Conflicts of Interest: The authors declare no conflicts of interests.

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