

A Baseline Investigation of Independence among 100 Community-Dwelling Centenarians in Turkey

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Abstract

This research reports on selected baseline data from 100 community-dwelling centenarians across seven provincial regions in Turkey. Data collection resulted from the deployment of a non-probability linear snowballing sampling technique. The independence of the centenarians was explored across 15 activities of daily living utilizing the Barthel Index-Activities of Daily Living (modified). Open-ended questions were put to subjects concerning their will-to-live, belief in the afterlife, level of contentment with life including family care, and fear of death. Findings indicate that more than 50% of the 100 subjects rated poorly on 10 of the 15 activities of daily living with 79 subjects requiring assistance with daily care. Only 42 subjects responded to the open-ended questions revealing a positive regard for family care, a measure of ambiguity surrounding contentment with life and a low will-to-live. Ongoing research efforts will be required by Turkey in order to understand the health status and functional performance of centenarians.

Keywords: Adaptability, autonomy, informal caregivers, oldest-old, intergenerational relationships, social justice.

*To come to one's end before the age of ninety,
means to die of disease, in other words, prematurely.
(Bauman cited in Kearsley, 1996, p.336)*

Introduction

According to the United Nations Population Fund (UNFPA) and Help Age International (2012) "The number of centenarians in the world is projected to increase from fewer than 316,000 in 2011 to 3.2 million in 2050" (p. 26). Centenarians are defined as people who have reached 100 years or over. However, there are those remarkable people who live beyond 100 years and are described as semi-centenarians (105-109 years) while those who are aged 110 years and over are known as super centenarians (Richmond, 2008).

While centenarians are exemplars of exceptional longevity they nevertheless represent a diverse population group in terms of overall health status and functional ability. According to McCormack (2007) “centenarians may well have adult children alive who would also fit the “aged” category because they are in their 60s, 70s, or even 80s, yet we know little about these intergenerational relationships” (p. 55). Tufan (2007) draws attention to the fact that the fastest growing segment of the Turkish population is to be found among the 80 and over age group. The Turkish Statistical Institute Population Projections 2013-2075 show that the “proportion of citizens aged >65 years is now 7.5%, with the proportion expected to increase to 10.2% by 2023, 21% by 2050 and 28% by 2075” (p. 14). While the study of aging and old age in Turkey has made some inroads in recent years there has been little or no specific undertaking to place the study of centenarians on the gerontological research agenda. Poon and Cheung (2012a) examined centenarian research over the past two decades and made no reference to centenarian research in Turkey. Likewise, Herm, Cheung and Poulain (2012) focusing on the demographic analysis of centenarians worldwide provided no relevant data from Turkey. This baseline research represents an important effort to gain initial understandings on the level of ‘independence’ in the activities of daily living and the ‘will-to-live’ among 100 community-dwelling centenarians in Turkey. In addition, subjects were also requested to respond to matters relating to contentment with life, provision of care, fear of death and belief in the afterlife.

Human Longevity and Independence

Research on advanced old age must understand that each life is not only unique but that it has also been framed within a time and social-cultural space with implications for continuous adaptation and meaning (Rowles & Watkins, 2003). Health professionals and gerontologists might well heed the advice of Stone (2003) “pay attention to how people define themselves, rather than rely too closely on reified constructions of what people are not supposed to be able to do” (p. 60). Future research undertakings that focus upon in-depth studies of centenarians need to conceptualize person agency “around coping or compensation, drawing insights from Baltes’ (1997) model of selective optimization and compensation” (Grenier & Phillipson, 2014, p. 70). Anson et al. (2012) suggest that research on exceptionally long-lived individuals must necessarily consider a combination of genetic, biological, environmental and stochastic or random events. There are those individuals who have benefitted from a complex mix of factors that have enabled them to experience what Hillman (1999) terms ‘*lasting*’ taken to mean living a life well beyond what is expected for the majority of people within a specific older population cohort. Hillman argues that while human longevity is on the increase we have to consider “if that extension merely adds more days of pain, sorrow, and incapacity” (p. 26).

Influences on Life Satisfaction

Bishop et al. (2011) in a study of 137 centenarians found that life satisfaction and subjective well-being were influenced to the extent that they experienced negative emotions. Tafaro et al. (2008) in a study of stress among centenarians reported that half of their study sample showed little or no depression as well as displaying low anxiety to life related stresses. The same research group also found that for the centenarians “aging of all apparatuses was slowed down by a healthy lifestyle and also by a good adaptability that allowed positive and effective response to stress throughout their whole life” (p. 353). A study by Auberg et al. (2005) involving a small group of persons aged 80-95 showed that when looking at life satisfaction, activity, independence and adaptation that all four were influenced in a positive manner if they felt that they had control and influence over help and access to reliable support services.

The landmark study by Sixsmith (1986) with community-dwelling older people revealed that a key factor contributing to a sense of independence was to remain living in their own homes. While dementia related disorders are known to exist among centenarians Poon et al. (2012b) remind us that “The question still exists on the rate of change of cognition among centenarians and whether centenarians are statistical outliers or expert survivors who could test the applicability of our current aging theories and models” (p. 363). For those older people who are long lived there is the issue of the perceived meaningfulness of life and the will to live. Carmel (2001) believes “The will to live is one of the most important existential issues that has concerned all religions and many of the great philosophers” (p. 949). The same researcher points to the fact that all cultures have their way of dealing with the meanings of life and death and “the will to live is related to indicators of psycho-social well-being such as self-esteem, satisfactions with life, and social support” (p. 950). Perhaps the reason for the unwillingness among some people to live to 100 years and over is the likelihood for illness and disability occurring in advanced old age (Kanowski, 1984; Lampert, 2000).

Damron-Rodriguez and Carmel (2014) provide a cautionary note for caregivers of older people “First of all, we must educate people that the will to live is dynamic-not all people want to live to the same degree, and not all the time” (p. 33).

Longer Life: The Issue of Dependency

The possibility of becoming care dependent among long lived people in Turkey represents a reality when recognition is given to the fact that 54% of the people aged 80 and above are care dependent (Tufan, 2007). Helmchen, Kanowski and Lauter (2006) provide evidence that shows that there is a significant relation between loss of opportunity for participation and physical, mental and psychological losses (see also, Oswald et al; 2006; Staudinger & Häfner, 2008).

Willcox et al. (2008) reporting on their assessment of the Okinawa Centenarian Study showed that for the most part super centenarians displayed little evidence of clinically apparent disease until close to the end of their lives. Galioto et al. (2008) revealed that centenarians tend to display more positive cardiovascular profiles when compared with younger groups of older people. Table 1 illustrates the types of medical conditions that help to explain the death of 439 older Turkish citizens. It seems that centenarians possess the ability to markedly delay the onset of co-morbidities more commonly found in younger cohorts of older people. The health behavior of among the elderly in Turkey has been reported in a national research study that resulted in the Turkey Atlas of Gerontology known as Gero Atlas (Tufan, 2009). The preceding nationally based study is ongoing with plans to continue until 2024.

Table 1: Medical Conditions of Older People Aged 65 + Years by Number of Related Deaths Across Seven (7) Regions in Turkey for the Period (2010-2012)

Cause of death	MAR	AEG	MED	CEN	BLC	EAST	SEAST	TOTAL
Circulatory diseases	34	23	28	17	21	27	30	180
Tumors	19	11	27	23	17	13	14	124
Respiratory diseases	5	6	3	4	5	4	4	31
Gastrointestinal diseases	4	4	5	4	7	4	2	30
Intercellular exchange problems	2	1	2	2	1	2	1	11
Nervous system problems	1	2	1	1	1	2	1	9
Alzheimer	1	1	2	2	1	0	0	7
Infections and parasites	1	0	1	1	1	1	1	6
Urogenital diseases	1	1	0	0	1	2	1	6
Suicide	1	0	0	1	0	0	0	2
Blood-making organ diseases	0	1	0	0	0	0	0	1
Unknown	2	3	4	2	4	8	9	32
TOTAL	71	53	73	57	59	63	63	439

Note: MAR = Marmara Region, AEG = Aegean Region, MED = Mediterranean Region, CEN = Central Anatolia Region, BLC = Black Sea Region, EAST = Eastern Anatolia Region, and SEAST = Southeastern Anatolia Region

Methods

This baseline study conducted over the period 2010-2013 inclusive of compilation of data was funded by TUBITAK (The Scientific and Technological Research Council of Turkey) and the Turkish National Association of Social and Applied Gerontology. Data were collected using a snowballing sampling method across seven major cities in seven provincial regions in order to make contact with community-dwelling centenarians who tend to represent a hidden subgroup of the Turkish population. The study represents the first Turkish endeavor to enter the world of centenarians in order to gain preliminary insights into their level of independence in terms of Activities of Daily Living including their feelings surrounding the ‘Will-to-Live’. As ‘centenarians’ are typically defined as those persons 100 years and over, this broad definition is used in this study. In line with ethical research practice the study utilized the informed consent process (Christensen et al, 1995; Escobedo et al. 2007; Sin, 2005) resulting in a total participation of 100 subjects in the assessment of activities of daily living (ADLs).

Subjects selected for interview and who were unable to provide an identity card to align with the records of TURKSTAT (Turkish Statistical Institute) and/or who were unavailable or did not initially consent to participate were excluded from this baseline study. In relation to the list of additional areas of interest involving the will to live, contentment with life and provision of care, fear of death, and belief in the afterlife, a total of 58 subjects either directly or by way of a caregiver decision refused to respond to the preceding areas of research interest.

Activities of Daily Living

Lawton and Brody (1969) have been given credit for their pioneering work in describing two levels of human activities, namely activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The ADLs relate to activities such as personal care involving bathing, toileting and eating while the IADLs refer to more complex tasks that comprise the use of the telephone, shopping, food preparation, general housekeeping, management of medication and participation in community life (see Fontane, 1996; Kempen & Suurmeijer, 1990; Stull, Kercher & Kosloski, 1996; Fricke, 2010). The primary focus of the research was to determine the level of independence of subjects in relation to their activities of daily living by using the Modified Barthel Index (Schädler et al; 2009). The main aim of the Barthel Index-activities of daily living (modified) is to establish the degree of independence from any help or assistance, physical or verbal. The Barthel Index has been reported to have high reliability (Colin et al; 1988). The MBI is used to assess the ability of an individual to achieve certain activities of daily living without assistance and includes self-care (feeding, grooming, bathing, dressing, bowel and bladder care and toilet use) and mobility (ambulation and stair climbing). Direct testing of the individual is not an absolute requirement, as information can be derived from informal family caregivers, friends and nurses. Activities of daily living are normally assessed in accordance with a 0-4 scale. As the Barthel index primarily deals with motor skills, Prodiga et al. (1996) developed six cognitive items to the index.

The decision was made not to utilize the common 4 points (0-3) scale in favor of a modified 5 points (0-4) scale to assess the level of independence for activities of daily living which has been successfully used with people suffering from neurological diseases. An important aspect of the preceding assessment tool is that it can measure a subject's overall functional performance within 20 to 30 minutes while at the same time being affordable. Training in the use of the instrument can be accomplished in under two hours and can be utilized by a range of personnel including primary family caregivers of older care recipients. In many instances throughout this study there was a high reliance on the cooperation and support of a family member who generally performed the primary caregiver role for the older person 100 years or older.

Subjects

This baseline study involved the assessment of activities of daily living of 80 female and 20 male subjects who met the requirements for classification as centenarians. Within the study group of 100 subjects 97 had outlived their respective spouses. Those with spouses still alive comprised one female subject and 2 male subjects. The age composition for the 100 subjects showed that 19 were 100, 31 were 101, 32 were 102, 15 were 103 and 3 were 104 years old. The average age of the study group was calculated to be 101.5 years (± 1.1). The majority of the subjects (N=58) comprising 52 females and six males were deemed to be essentially illiterate. A total of 23 subjects (3 males and 20 females) displayed a measure of literacy despite having no formal schooling experience. Those completing primary education amounted to 14 subjects made up of five females and nine males. Those completing secondary education were 5 in number comprising 3 females and 2 males. The generally low level of formal educational attainment across the study group is possibly explained by historical difficulties arising from limited life chances for accessing formal education including the earlier traditional practice of discouraging females to acquire a formal education. The majority of subjects (N=88) indicated that they were not in receipt of any income while the remaining number of subjects (N=12) revealed that they had access to regular income.

Results

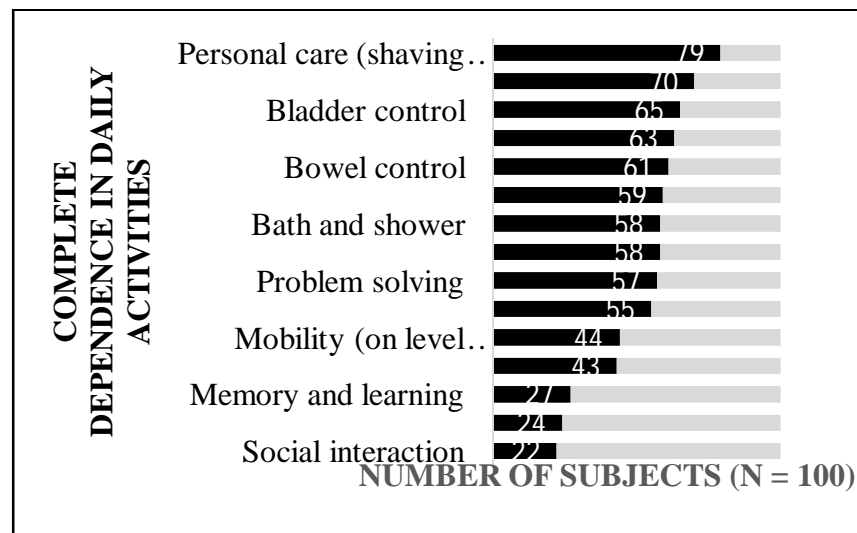
Activities of Daily Living: Level of Dependence

Results of the research involving 100 Turkish subjects aged 100 and over provided valuable insights into functional performance on activities of daily living (ADLs). Utilizing the Modified Barthel Index empirical data were gathered on 15 of the listed 16 activities of daily living (ADLs) with the exclusion of assessment on wheel chair use due to the extremely low number of subjects in this category (N=3).

The level of dependence for each activity of daily living was determined for each individual and is reflected in Figure 1 with the aggregate numbers of subjects displaying dependency for each respective activity of daily living. Physical losses in advanced older age as shown in the research literature (Mendes de Leon et al; 1996; Milanovic et al; 2013) are evidenced in the findings of this study. The highest level of dependency relates to personal care with 79 of the 100 subjects displaying complete dependency on caregiver support for this ADL. On the other hand, the ADL relating to social interactions showed that only 22 subjects were completely dependent on caregiver support for engagement in this area of personal performance.

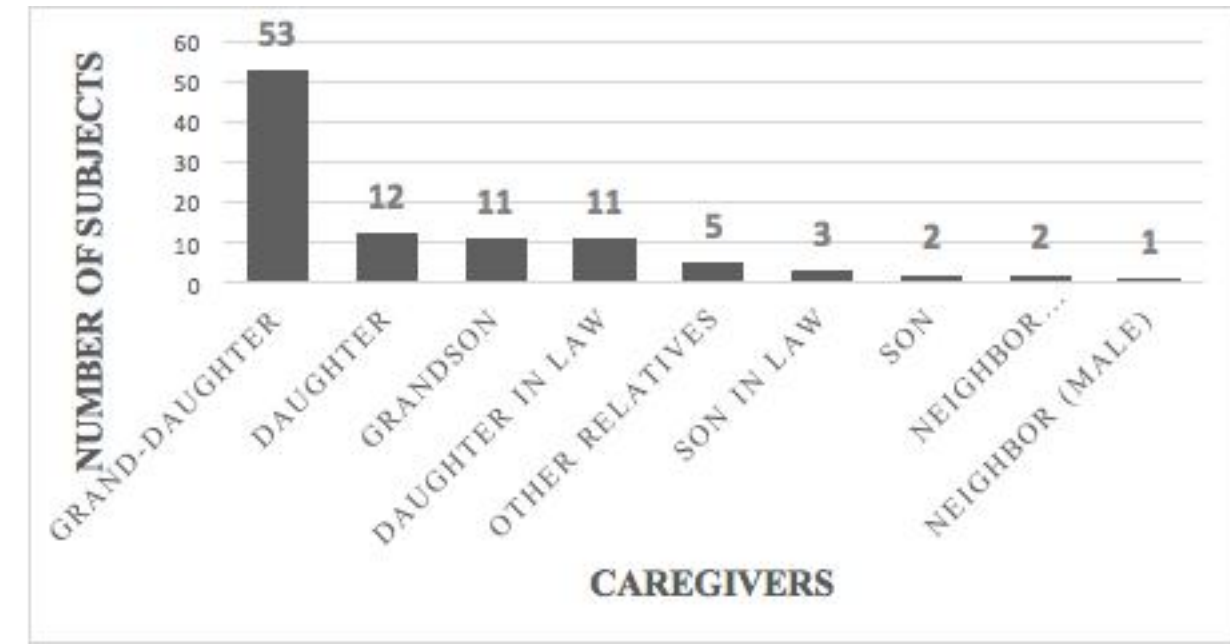
Altogether Figure 1 shows that 10 of the 15 ADLs recorded more than 50% of subjects displaying dependency related support needs. While gender differences were detected in the ADLs relating to personal care and eating this was not the case across the remaining ADLs. In essence, it was determined that for this study that the trend towards dependency for subjects aged 100 years and over was reasonably balanced across the genders.

Figure 1. Number of subjects displaying complete dependence across 15 activities of daily living.



Caregivers

Gerontological research shows that old aged care recipients are generally cared for by female family members (Department of Health and Human Services, 1998; Rice, Walker & Main, 2008; Savage & Bailey, 2004). Findings from a national research project aimed at building an Atlas of Gerontology for Turkey showed that primary caregivers of care dependent old aged individuals are generally their spouses, daughters and daughters-in-law (Tufan, 2009). Figure 2 shows that this is still the case for the 100 centenarians that were the focus of the present research study. Among the female informal caregivers in this study the number of granddaughters fulfilling the care giving role numbered 53 in total. It is also interesting that 11 grandsons were also engaged as family caregivers resulting in a total of 64 grandchildren taking on the care giving role. The number of daughters taking care of their parents amounted to 12 with 2 sons fulfilling a caregiver role. Support provided by others not part of immediate blood relatives involved 11 daughters-in-law and 3 sons-in-law. The predominance of grandchildren as informal caregivers is no doubt a reflection of the fact that the adult children of the centenarians are themselves entering advanced older age and often in need of care giving support. The average age of caregivers was 55.9 (± 11.9) with an age range of 32 years to 78 years. The median age for the caregiver group was 54.5 years with 25% of the caregivers being younger than 47 years, and 25% older than 64.8 years. The latter group involved adult children, sons-in-law and daughters-in-law as primary caregivers. Figure 2 provides an illustration of the overall profile of informal caregivers of centenarian care recipients which at the same time showing clear evidence of the predominance of females as the major caregivers. It would appear reasonable to advocate that with grandchildren playing a significant role in care giving of centenarians that research be undertaken to monitor, assess and understand the effect on intergenerational relationships.

Figure 2. Profile of informal caregivers across 100 centenarians

Contentment with Life and Provision of Care, Fear of Death, Belief in the Afterlife

This study provided the opportunity to communicate directly with 42 of the subjects concerning questions about their contentment with life, and provision of care, fear of death, and belief in the afterlife. The reasons for refusal of the remaining 58 subjects were not pursued, and while no doubt complex, may have in some instances involved concerns among some caregivers that they might receive negative responses on the level of care. There is of course the probability that the preceding areas of interest might have made some subjects or their respective caregivers uncomfortable including the possibility of untoward outcomes on the health and well-being of their older family member. Responses from subjects were solicited by using a scale of 11 points (0-10) with response categories ranging from (0: not at all to 10: strongly agree). In order to assist the subjects to comprehend the nature of response options a “visual scale” was used rather than numbers. Subjects were shown a picture of 11 stairs rising upwards with an explanation of the optional responses attached to each step on the staircase. Each subject was invited to indicate the appropriate step relating to each respective question. Table 2 shows the median scores and corresponding average values for the four preceding areas of investigation. The median value for contentment with life was 5 with an average value of 4.8 indicating the presence of some ambiguity in relation to this area of inquiry. The fear of death is quite low with a median score of 3 and an average value of 2.9 indicating a general acceptance of death being the impending destiny in a long life. The belief in the afterlife is high, with a median value of 8 and an average value of 7.5, while contentment with the provision care was judged very favorably with a median score of 8 with an average recording of 7.5.

Table 2. Results of the responses by 42 subjects about contentment with life, fear of death, belief in after-life and contentment with provision of care.

	Contentment with life	Fear of death	Belief in after-life	Contentment with provision of care
Average value	4.80	2.90	7.50	8.20
Median	5.00	3.00	8.00	8.00
Standard Deviation	2.20	1.90	2.00	1.20

Will to Live

Based upon the informed consent process and in line with the research undertaken by Carmel (2011) on the will to live (WTL), 42 subjects were subsequently asked whether they had a strong will to continue living in accordance with a nominated response from one of following three options, yes, no, I am not certain.

Results showed that 29 (69%) of subjects answered that they had lost the will to live. On the other hand, 9 (21%) of the subjects indicated that their will to live was still strong while 4 (10%) of subjects were ambivalent in relation to their will to live. When the preceding result is compared to the previous findings about contentment with life, it is seen that there is a corresponding relationship between low contentment with life and low will to live. This finding is in line with the research undertaken by Carmel (2011) who indicated that both longitudinal and cross-sectional studies revealed significant negative correlations between age and the will to live. According to Carmel the will to live represents an important indicator of an older person's general sense of well-being. On the other hand, it is seen that belief in the afterlife is high and fear of death is low for the 42 subjects engaged in this section of the research study.

Discussion

Understandably, the findings emanating from this non-probability study cannot be generalized across the heterogeneous population of centenarians in Turkey. However, the use of the snowballing method of sampling in the context of the present study provided a valuable tool for gaining baseline insights into centenarians who are currently outside mainstream social research in Turkey. While the present study involved an assessment of the function of centenarians across a range of activities of daily living it is important to take note of the perspective offered by Lawton and Brody (1969) "Assessment is not, of course, an end in itself. Its basic purpose is to establish and carry out treatment goals" (p.183). This study found that there exists a high level of dependency among the subjects 100 years and over in terms of their performance across a set of activities of daily living. Cognitive awareness is only partially better which compounds the role of informal caregivers. Cho, Martin and Poon (2012) reporting on their Georgia Centenarian Study showed centenarians did not satisfy the criteria of 'successful aging' as proposed by Rowe and Kahn (1997). Cho, Martin and Poon (2012) contend however "It may be difficult to achieve successful aging in extremely late life. There is still no agreement on the definition of successful aging, and future work needs to expand the criteria for successful aging" (p.6). Pruchno, Wilson-Genderson and Cartwright (2010) offer a critical review of research on successful aging by putting forward a case for more inclusive research involving the very old and centenarians. In particular, they propose a conceptual approach to the study of successful aging that includes and integrates both objective and subjective considerations. There must necessarily be a fundamental shift in current thinking which in most cases excludes the possibility of successful adaptation among the oldest-old despite the presence of disabilities and comorbidities.

Current and future social planners will find it increasingly difficult to argue against Baltes and Smith (2003) who presented a strong case for more serious attention to be given to the oldest-old. Perry (1995) argues "The study of adaptation to substantial changes in environment or life circumstance can be particularly revealing to understanding aging well" (p.161). It would appear that work by Haak, Fange, Iwarsson and Ivanoff (2007); Manzo (2005); Rapoport (1995); Rowles and Watkins (2003); and Sixsmith (1986) offer fruitful avenues for examining the influence of 'Aging in Place' on older people's perception of independence. Work by Andersen-Ranberg, Schroll and Jeune (2001) suggests that while centenarians rate poorly on a range of health dimensions there are many who maintain a commendable level of autonomy. However, independence in later life can in many situations be fostered with the help of assistance from caregivers (Kruse, 2007). While this might be the case, it would seem appropriate that policy makers in Turkey give due recognition to the fact that the growth of centenarians in Australia has raised the disturbing fact that the majority of informal caregivers of long-lived parents or grandparents are "untrained and unmonitored caregivers with the burden falling disproportionately on women" (Richmond, 2008, p. 722). Redfoot and Houser (2005) provide an important message for policy makers and health care professionals "Finally, policies and programs that address needs at the national level cannot ignore the individual needs and aspirations both of those who need long-term care and those who would provide that care" (p.45).

It will be essential that future researchers' pay attention to the need to adopt ethical approaches to the 'informed consent' process which can be easily avoided when dealing with centenarians and their older caregivers (Christensen, et al; 1995; Lidz, Appelbaum, & Meisel, 1988; Sin, 2005). Herm, Cheung and Poulain (2012) provide an important research caveat when measuring extreme longevity "accurate identification of the age of centenarians is crucial. Inaccurate measurement of extreme ages has been reported in past populations and in populations without efficient civil registration" (p. 19).

It is clear from the work undertaken by Hutnik, Smith and Koch (2012) and Koch, Power and Kralik (2007) that more in-depth research is needed on the health and social care needs of the oldest-old. A diversity of research themes that attempt to better understand long-lived people can support new policy initiatives aimed at “the development of appropriate health and social interventions at this and earlier ages and can highlight valuable lessons about adding life to years rather than just years to life” (McCormack, 2007, p. 66). Poon and Cheung (2012a) call for improved methodological and theoretical approaches to longevity research while emphasizing “understanding the paradox that living longer is different from living well and that life is only worth living to a second century if it comes with satisfactory levels of health, autonomy, and functioning” (p. 10). Further studies on the oldest-old need to plan for the inclusion of ethically based approaches that can assist health professionals to engage in sensitive and caring discussions with centenarians and their caregivers on matters relating to advance care planning or end-of-life decisions.

Conclusion

Any future efforts by Turkey to build a sustainable welfare system including a long-term aged care workforce will need to be mindful of designing and implementing health service delivery options that focus on supporting independence, autonomy and the general well-being of centenarians and their respective caregivers. Turkey could well take an important step forward by building and sustaining an evidence-based research data register on centenarians in order to inform current and future aging strategies. Work by Nepal et al. (2011) and Fredrickson and Stolen (2007) on modelling approaches for planning the social and economic effects of population aging may prove useful resources to assist with the future development of policy options in Turkey. Future research on centenarians in Turkey should employ a range of rigorous research methodologies, both multi-disciplinary and interdisciplinary (Poon et al; 2012b) in order to gain a comprehensive understanding of the health status of centenarians and their caregivers. Sachdev, Levitan and Crawford (2012) provide useful advice for future research on centenarians that aims to maximize generalist ability of findings. It will be critically important to also understand how gender differences may help to explain the influences and pathways taken by men and women to achieve extreme old age in Turkey (Calasanti, 2010; Franceschi et al; 2000; Pruchno, Wilson-Genderson, & Cartwright, 2010). While Turkey will face major challenges to implement a balanced and sustainable welfare and health care system, it remains to be seen if serious policy attention will be given to the moral, ethical and social justice issues surrounding the provision of quality based health services to centenarians and their respective family caregivers.

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