Caregiving in older ages and the quality of life – which factors of caring are important?

1 A provision of informal care as a part of active ageing policies

Nowadays, almost all populations around the world are ageing due to demographic transition from high fertility and high mortality settings into low fertility and low mortality settings (Timonen 2008). Active ageing is both a concept and a policy that has been developed in response to these rapid changes in age structure of populations in Europe and elsewhere. Active ageing advocates, according to Walker and Maltby (2012: S127), a "transition from the perception of older adults as largely passive recipients of welfare", towards a notion of older individuals as more active actors involved in economic, social, and political activities in order to maximize their own quality of life.

The concept of active ageing involves more different roles. Guiding principles of active ageing are employment, participation in society (volunteering, provision of care, leisure activities, life-long learning, mental and physical activities) and independent living (EU council 2012, European commission 2013). Consequences of all encompassed activities are supposed to be predominantly positive and no variation of their aspects and impacts was distinguished. Still, I suppose that for example provision of care is often exhausting, and also involuntary activity, which in many cases does not improve the quality of life of older people. Caregiving has a potential to raise life satisfaction among older people, but only under certain conditions (Moen et al 1995). Some of the most important conditions (e.g. intensity, multiplicity or voluntariness of care and a context of social policies) are mentioned below in the text or somehow incorporated to analysis.

This study investigates which dimensions of subjective quality of life are connected to provision of informal care and how this connection depends on the intensity and multiplicity of caregiving. Data from the project Survey of Health, Ageing and Retirement in Europe are utilized to deal with this topic. Summary of a theoretical background is followed by a presentation of the results and a discussion of possible implications of finding of this study.

2 Costs and benefits of informal caregiving

The basic assumption of active ageing theory is the notion that higher social participation leads to increased personal health and well-being (Walker 2009). This notion is highly compatible with the main idea of the theory of role accumulation. This theory argues that role accumulation has mostly positive outcomes in life (Sieber 1974). Enhancing effect of additional roles is supported by some empirical research. More particularly, even studies focused on the effect of caregiving on life satisfaction in older ages found positive consequences of care provision (De Jong Gierveld, Dykstra 2008, Potočnik, Sonnentag 2013).

Not all authors agree with the beneficial effect of additional roles in older adults. According to the theory of role strain, involvement in multiple roles under normal conditions leads to conflicts in demands or obligations between competing roles (Goode 1960). Role strain of older caregivers is also well-documented in empirical studies (Mui 1995, Reid, Hardy 1999, Colombo et al. 2011). It is evident from the results of cited papers that the effect of caregiving (and also of many other roles) is dependent on the context. Moen and colleagues (1995) and Penning (1998) state this same conclusion in their study.

The effect of the provision of care on quality of life in older carers indeed depends on specific conditions. This topic has not been systematically elaborated, but it seems that caregiving has more positive outcomes, if it is less intensive (Broe et al. 1999, Colombo et al. 2011, Van Groenou et al. 2013), more voluntary (Szinovacz, Davey 2008, Van Groenou et al. 2013) and more rewarded (Wahrendorf, Siegrist 2010, Neuberger, Haberkern 2014). The next paragraphs explain these factors in more detail.

The intensity of caregiving is quite clear issue – more intensive care is associated with higher burden and it is less often involuntary at the same time (Igel et al. 2009). Voluntary care means that a caregiver has a choice over her provision of care. The opposite is involuntary, normative (Szinovacz 2008) or obligatory (Igel et al. 2009) informal care – this type of involuntary care exists mostly in situations where formal care is not available and caregiver is forced to provide (often intensive) practical help for a close person. Involuntary care is more prevalent in countries with less accessible social services. The institutional structures represented by social services are more important than cultural norms in the explanation of this issue (Igel et al. 2009). This paper controls availability of formal care as the only context variable, while the interaction between formal care and care provided by respondent is more important for us than the effect of accessibility of formal care on the quality of life itself. Finally, more rewarded caregiving (as the last factor of care) means that this activity is socially appreciated (Siegrist, Wahrendorf 2009) or in compliance with normative obligations of society (Neuberger, Haberkern 2014). I do not expect that social rewards of caregiving have impact on feelings of loneliness, meaning of life or overload as specific feelings that are related to caregiving directly, not through social rewards.

The multiplicity of care has quite unclear impact on quality of life. Multiple care is enhancing according to De Jong Gierveld and Dykstra (2008) or Pines and colleagues (2011), but harmful in the studies of Remennick (1999) or Chassin and colleagues (2010). I argue that direction of the effect of care provided to more recipients is connected to the intensity of provided care. The paper indicating provision of care of any frequency (at least once during the last three months) found out multiple caregiving as beneficial (De Jong Gierveld and Dykstra 2008). Unfortunately, most of the cited papers did not mention minimum intensity of care provided by respondents defined as “caregivers” (Remennick 1999, Chassin et al. 2010). It might be redundant to investigate the effect of both intensity of care and multiplicity of care. But it seems that the multiple role of caregiver have different quality than just a sum of their frequencies, because more roles are often in subjectively perceived tension or conflict (Goode 1960, Coverman 1989, Boudiny 2012), and the negative effect of the multiple care was found even if total amount of provided care was controlled (Chassin et al. 2010).

Most of the research oriented to the caregiving role multiplicity focus on “sandwiched generation” defined by age approximately between 35 and 50/60 and the provision of care for children and ageing parents at the same time (Remennick 1999, Chassin et al. 2010, Pines et al. 2011). Wassel (2006) or Grundy and Henretta (2006) argue that (also due to increasing life expectancy and extended younger adulthood) the experience of “being sandwiched” is much more common for people in their 50s, 60s or even 70s, when children are still partly dependent and parents are already too old to take care of yourself. According to Grundy and Henretta (2006), one third of women aged 55-69 years provide help to both child/ren and parent/s, which is higher prevalence than in originally defined sandwich generation. Lundholm and Malmberg (2009) are also aware of infrequent prevalence of original sandwich generation and focus on 55-years-old people with grandchildren and parents in potential need. I keep the logic of a “sandwiched generation” construct and extent it for other care recipients, namely spouse, grandchildren and other unspecified family or nonfamily members. This broader definition of informal caregiving allow me to control the whole set of caregiving relationships.

3 Subjective and objective quality of life

A general aim of many policy programs focused on older people – including active ageing policy – is to increase the quality of life of older people (Walker 2009). If we want to evaluate the quality of life, we need a definition and measurement of this construct. The main distinction existing in this area of research is distinction between objective indicators and subjective indicators of quality of life. Typical objective indicators used in social gerontology are e.g. number of diagnosed diseases, material conditions or social networks; representatives of subjective indicators are e.g. subjectively assessed health status or life satisfaction (Fernandéz-Ballesteros 2011, King et al. 2014). This paper is more interested in a subjective evaluation of life, so I will focus just on the group of subjective indicators.

Even though I focus more closely on the subjective assessment of life in general, there are still various concepts and their various measurements. More concepts are interpreted in a very similar way and used almost as synonyms – the subjective quality of life, life satisfaction, well-being, psychological distress, etc. (Katz 2009). I consider here only measurement of these constructs in the studies focused on the effect of caregiving on life satisfaction among older adults. Well-being in older ages has been measured in these studies mainly by multiple-item scales such as CASP-12 (Siegrist, Wahrendorf 2009, Potočnik, Sonnentag 2013, Roll, Litwin 2014), life satisfaction index-A (Broe et al. 1999), WHOQL-BREF inventory (Lowenstein 2007), or scale indicating depressive symptoms CES-D (Baydar, Brooks-Gun 1998, Reid, Hardy 1999, McIvane et al. 2007, Silverstein et al. 1996). On the other hand, life satisfaction has been measured overally by one direct question (Katz 2009, Lin et al. 2011, Roll, Litwin 2014). However, these concepts have been often mixed up with others (e.g. happiness, distress, mood, affect, depression) and differences between them usually have not been clarified (Lowenstein 2007, McIlvane et al. 2007, Roll and Litwin 2014).

Indeed, the concepts of subjective quality of life, well being, happiness and satisfaction with life have been often equated in the research (Andrews 1974, Bowling 2005a). All of these concepts are more or less general, multidimensional and potentially encompass more domains (Bowling 2005a). I argue that, besides the extensive existing research examining life satisfaction generally, it is also useful to research specific domains of life satisfaction in older ages. More elaborated is the study of Di Novi (2013), where the effects of four subdomains of CASP-12 questionnaire – control, autonomy, self-realization and pleasure – are analyzed separately. These four subdomains are interpreted as meaningful dimensions of quality of life in later life. Nevertheless, this novelty is not theoretically grounded and interpretation of the results is not well developed in the paper (Di Novi 2013).

Previous research encompasses not only a substantial number of studies on well-being/life satisfaction and extension made by Di Novi (2013), but some of the papers also work with other meaningful dimensions of subjective quality of life. First, De Jong Gierveld and Dykstra (2008) found a positive effect of (multiple) care provision on loneliness. Tsai and colleagues (2013: 568) claim that „One important issue concerning aging is (...) loneliness caused by the evolution of intergenerational contact in a changing society“. Loneliness is a very prevalent phenomenon in older ages (Shiovitz-Ezra 2013) strongly related to depression (Tsai et al. 2013). I investigate potential of caregiving to reduce loneliness. Second, I explore association of caregiving and meaning of life, which was found in the study of Pines and colleagues (2011) – provision of care seems to be the one of possible answers to the existential issues in late mid-life. Di Novi (2013) used in a similar way a concept of self-realization, which is associated to caregiving because of fulfilment of social roles, but also of one’s ethic and one’s life. Third, I also elaborate the association of caregiving and overload to test assumption of role strain (Goode 1960) under various caregiving conditions. A direct question at this concept has not been analyzed yet. I expect that the effect of regular care on these three dimensions of subjective quality of life differs from the effect on subjective quality of life itself, which is mostly insignificant (Baydar, Brooks-Gun 1998, Siegrist, Wahrendorf 2009, Roll, Litwin 2013) or negative (Broe et al 1999, Ekwall et al 2004, Colombo et al 2011).

To sum up, the paper examines the association of caregiving and three dimensions of subjective quality of life – important dimensions of the quality of life in older ages, which supposed to be related to the provision of care. I hypothesize that the provision of care reduce loneliness and increase meaningfulness of life (role enhancement hypothesis), but also increase perceived overload (role strain hypothesis). Furthermore, I hypothesize that the effect of caregiving on all three aspects of subjective quality of life is more negative/less positive in a situation, where a caregiver provides more intensive care and where a caregiver provides care to more recipients. Finally, I hypothesize that the effect of caregiving is more positive/less negative in countries with higher accessibility of formal care, because provision of care is more voluntary and optional in this situation.

4 Data, measurement and methods

4.1 Data

This paper utilizes data from the Survey of Health, Ageing and Retirement in Europe (SHARE). SHARE is a panel cross-national project, where data are collected by computer-assisted personal interviews. 19 countries have already attended at least one wave of this project; I use data from the last released wave (wave 4) collected on representative samples in 2011. Overall, data from 15 countries are analyzed in this study – three countries did not participate in wave 4 and some indicators were not measured in Estonia. This dataset enables me to analyze quite recent data from various parts of Europe collected at one time point.

Descriptive statistics, including the countries and sizes of their samples, are listed in Table 1. Some respondents from the original sample were dropped due to missing values (for example, only one respondent from a household was asked about provision of care) and also the spouses of original respondents under the age of 50 years were omitted from the analysis. The whole sample has 27 431 respondents after deletions. The sample size for each country can be reconstructed from the size of overall sample and proportions of the countries in percents – number varies from 863 respondents for Germany to 3 283 for France. Individual cases are nested in countries in the analysis to control differences in availability of formal care. All characteristics of respondents are level-1 variables except of the only level-2 variable reporting standardized proportion of employees in social services.

4.2 Dependent variables

Three single-item variables have been employed to indicate the three dimensions of subjective quality of life. Loneliness was measured by the question "How much do you feel lonely? Often/some of the time/hardly ever or never". This single-item measurement of loneliness highly correlates with the 20-item original UCLA scale of loneliness and seems to be a valid measurement of loneliness (Theeke 2009, Aartsen, Jylhä 2011, Park et al. 2013). Questions about the meaning of life and overload are originally items of CASP-12 scale measuring quality of life in older ages; items from this scale have been used as indicators of specific concepts repeatedly (Jansen et al. 2010, Towers et al. 2014). The meaning of life is indicated by the item "I feel that my life has meaning" and negative evaluation of item "I can do the things that I want to do" indicates overload. There are options "Often/Sometimes/Not often/Never" for the evaluation of both of these items. Scales for indicators of loneliness and meaning were reversed, so higher values indicate higher loneliness, higher meaning and higher overload in the analysis.

4.3 Main explanatory variable

This study uses provision of care as the main explanatory variable of subjective quality of life. Two independent variables indicating caregiving are designed to examine two dimensions of care – its frequency and multiplicity. These variables were constructed from SHARE module

“Social support” questioning provision and intensity of caregiving provided to parents and parents-in-law, to spouse, children, grandchildren and many other relatives, as well as to friends and other nonrelatives. First variable indicate provision of care almost every week or more; second variable indicate provision of care almost daily. Value of each variable represents a number of caregiving relationships of a given intensity – with no caregiving relationship of a given intensity as a reference category. Hence, indicator of care provided every week or more often have values 0, 1, 2, 3 and 4 or more, whereas indicator of care provided every week or more often have values 0, 1, 2 and 3 or more. Thus, I can compare the effect of very intensive caregiving to less intensive, but still regular provision of care by comparing result for these two variables. I do not expect that occasional care provided e.g. few times a year significantly changes subjective quality of life (Broe et al. 1999, Colombo et al. 2011). Furthermore, I compare effect of number of caregiving relationships at the same time – multiple intensive relationships are expected to have more negative consequences then opposite ones.

4.4 Control variables

There are utilized various continuous and categorical control variables in the analysis, almost all of them are characteristics of respondent measured on the first level of the data structure. Most of the continuous controls are measures of family structure: number of surviving parents (together with parents-in-law), number of siblings, number of children and number of grandchildren. These four variables are topcoded – approximately one percent of the highest and rarest values are merged into one category to eliminate outliers. The last measure of family structure is a binary variable “partner lives in the same household” (yes/no). Family members can increase demand of caregiving, but they can also lower care burden of the respondent by their own provision of care (Di Novi 2013). Just two other continuous control variables remain in the list: age and age squared of the respondent. All continuous variables were centred on their mean to make the intercepts easily interpretable.

The other categorical controls are the following characteristics of the respondent: sex (male/female), subjective health status (category “unhealthy” consists of former categories poor and fair, category “healthy” from former options good, very good and excellent; this dichotomization is widely used and does not affect result, see e.g. Contoyannis, Jones 2004, Pico 2007, Di Novi 2013), employment status (not working, working part-time, working full-time), and finally the education of the respondent (ISCED scale was categorized to three categories 0-1, 2-4 and 5-6; this categorization is according to International Standard Classification of Occupations 2012 the most meaningful).

Finally, the percentage of employees in health and social services according to the OECD database 2011 is controlled as the only level-2 variable. Percentage of employees in health and social services is “the best measurable public substitute for practical support between generations” (Brandt, Deindl 2013) and apparently also the most frequently used one (Brandt et al. 2009, Igel et al. 2009, Schmid et al. 2012, Brandt, Deindl 2013). This indicator of the availability of formal care has been standardized to make fixed effects more easily interpretable.