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Deliverable D2.1: Existing Literature Report

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List of Acronyms and Abbreviations

Acronym/ abbreviation	
BIU	Bar Ilan University
ESR	Early Stage Researcher
LTC	Long-term care
WHO	World Health Organisation
WP	Work package

Contents

Deliverable 1: A report on existing literature related to ageism as a barrier to 1) provision of relevant support and services with a particular focus on social capital, health and social care services (ESRs 6-10) and 2) a barrier to appropriate and safe medication use (ESR 7).

1 Introduction

The difficulties of undertaking a literature search on *ageism* was discussed at the meeting in Brussels October 25th, 2019. At this time, Vania De La Fuente Nunez from the World Health Organisation (WHO) suggested that the search strategy on *ageism* conducted by WHO could be used as a template for all students and they could add their focus to this expert search. At the time of this deliverable (March 4th, 2019) though, the search strategy had not yet been finalised. It was therefore decided by this working group this deliverable would be kept as close to the ESRs' projects as possible in order they could use their expertise and gain experience in focusing on ageism as a barrier in health, social and pharmacological care as related to their particular studies. It also gave them the opportunity to learn from each other. This deliverable therefore reports on the literature databases each ESR used and goes on to give a resume of literature/ gaps in the literature salient to their searches. We arranged a series of group Skype meetings to agree how we would present this work. The group presented their work on an agreed template to give a uniformity to the deliverable, which we hope will prove useful to all ESRs. At the final group Skype meeting of March 4th, 2019, we discussed the learning that had taken place in the production of this deliverable and this is addressed in Section 3.

Section 2 shows the template used and presents the work of ESRs 6,8,9,10 (sections 2.1-2.4) to address existing literature related to ageism as a barrier to provision of relevant support and services with a particular focus on social capital, health and social care services. ESR 7 then reports on existing literature related to ageism a barrier to appropriate and safe medication use (see section 2.5).

2 Template for Deliverable 2

ESR Name and Institution

Title	
Literature review process:	e.g databases, search terms, etc.
Maximum of 200 words	
Literature report:	e.g gaps identified in the literature
Maximum of 300 words	
Conclusive remark:	

2.1 Laura Allen, ESR 6, Bar-Ilan University

The construction of autonomy and old age in long-term care

A report on existing literature related to ageism as a barrier to provision of relevant support and services with a particular focus on *long-term care (LTC)*

Literature Review Process

The research aim of project #6 is to understand how autonomy and old age are co-constructed in the context of the LTC setting. Ageist attitudes and behaviors are part of this process. The databases used to search the literature are limited to the availability within the Bar-Ilan University library and include: PubMed, Web of Science, APA PsychNET, PsycINFO (EBSCO), Academic Search Complete (EBSCO), and ProQuest. This search is limited to articles in English and published from 1990 to 2020. The search terms are categorized into three concepts.

Search terms related to concept 1 (C1) were gleaned from the search string used by a recent systematic review of ageism and long-term care (São José & Amado, 2017). C1 search terms include: long-term care, long term care, home care, senior housing, community care, day care center*, day care centre*, adult day care, residential care, nursing home*, skilled nursing facilit*, skilled nursing care, care home*, assisted living, continuing care retirement communit*, memory care. Concept 2 search terms aim to capture literature related to autonomy, with terms: autonomy, independence, preference, decision-making, choice, and agency. Concept 3 (C3) search terms related to ageism and the meaning of old age were adapted from a registered protocol of a prospective systematic review on assessment measures of ageism (Ayalon et al., 2018). C3 search terms include: ageism,

agism, ageist, agist, age discrimination, age stigma*, age prejudice, age stereotyp*, self-perception* of aging, self-perception* of ageing, attitude* toward* aging, age identity, subjective age, subjective aging, subjective ageing, self-ageism. C4 search terms include: policy, regulation, standard.

Literature Report

Literature on the autonomy has various definitions between contexts like political theory and biomedical ethics. It is a poly-semantic term, whose meaning heavily depends on the context. Biomedical ethicists and scholars have attempted to bring structure to the concept, particularly in gerontology and LTC. In the context of LTC, autonomous decision-making and action is intertwined with the meanings associated with old age and later life. Narratives of dependency and loss of autonomy characterize beliefs about old age and are oftentimes based in ageist assumptions.

At the same time, there have been changes in LTC policy across Europe in recent years, sprouting from person-centered care, with some frameworks evolving into a human rights-based approach. New standards and regulations have changed the decision-making context of the nursing home. While autonomy and beliefs about old age have been researched in long-term care, there is more to be understood about the interwoven nature of the two concepts since the recent LTC policy changes across Europe. Perspectives from stakeholders such as residents, family members, care staff, managers, and inspectors should be sought. Furthermore, literature on managers and inspectors of LTC is especially lacking. Their perspectives are important to understanding how autonomy and old age are co-constructed and manifested in the context of the LTC setting.

Conclusive Remark

Based on this review of the literature, research on autonomy and old age in LTC would benefit from an updated perspective. Ageism can be both a contributor to and an outcome of the connection between meanings of autonomy and old age. With a strong theoretical framework, these topics can be explored to understand their co-construction in LTC. Additionally, sufficient attention must be paid to the perspectives of the managers and the inspectors to fully capture the construction and meaning-making process in the LTC context.

2.2 Abodunrin Aminu, ESR 8, Robert Gordon University

Putting Ageism in context: Community vs. Long-term care oldest old

A report on existing literature related to ageism as a barrier to provision of relevant health and social care support and services with a particular focus on *oldest old individuals living in the community and residential homes*

Literature Review Process

This is a narrative review of literature carried out through combing of search engines available in the Robert Gordon University Library and her partner institutions. This literature search has been designed along the aim of this study, which is to explore the disparities in health and well-being of oldest old individuals aged 80+ dwelling in community and care homes, and the ageism-related factors that contributes to these disparities.

The keywords utilised in the literature search included:

- Ageism or Agism or "Age discrimination*" or Ageist or Agist or "Negative attitude"

  AND
- Disparit* or Inequalit*

  AND
- "Nursing home*" or "Care home*" or "Residential home*" or "Sheltered home*"

  AND
- Community

  AND
- "Older people" or "Elderly", "Oldest old" or "4th Stage" or "Older adult*" or "80+"

The search engines that were explored included *MedLine, Scopus, SAGE Knowledge, Science Direct, Web of Science, EBScoHost, and NICE.* The search on these engines generated several outputs and the reviewed literature were identified by streamlining the search to:

- Type: Article
- Relevancy: Search word contained in Title and/or Abstract
- Date: 2 Decades (1999 - 2019)
- Language: English

Literature Report

With increasing life expectancy of the population in many countries, there may be increasing demand for long term care due to frailty that accompanies old age, which can lead to potential burden in public health and healthcare systems throughout the world (Fabbricotti et al., 2013). As the population of older people continues to increase globally, the oldest old group (80+) became the fastest growing segment of the population (Gjonca et al., 2010). Although the popular narrative is that this group of individuals are most vulnerable to disease and consequently the most dependent on health and social care resources, oldest old people may also be regarded as individuals with the real survival traits among their peers (Fabbricotti et al., 2013).

Discrimination in health and social care has been a major topic of discussion in the very recent times because of its attending effect on health and well-being of the older population (Bird and Bogart, 2001). Whilst it is difficult to have a definite unit for measuring this huge social challenge, several efforts have been made to explain how this is related to health outcomes. For instance, a study examined the health correlates of racial discrimination that occurs within a health care setting (Shavers et al., 2012). Furthermore, an earlier study indicated that there is disparity in health outcomes between oldest old individuals living in community and care homes (Gu et al., 2007).

This has been associated with factors such as inactivity, cost of treatment, disabilities and the disposition of care providers working with these individuals. Nonetheless, it was difficult identifying from literature search, the role of discrimination of the health and social care of oldest old individuals in Scotland.

Conclusive Remark

Despite the huge campaign by health organizations, there are paucity of research that explore the objectives of this study. The literature review showed that there has been little or no output comparing oldest old individuals in the community and care homes in the UK.

2.3 Atiqur Rahman, ESR 9, Linköping University

Ageism in the care service system: The case of care service assessment for older people 65+ with dementia

Literature Review Process

The overall aim is to investigate how stereotypical notions about aging and dementia might influence policies, organizational practices as well as the actual interaction in the needs assessment meetings and decisions about social care services for people with dementia aged 65 and over.

The research project considers five scientific databases to produce a systematic literature review: Web of Science, PubMed, Scopus, PsycINFO and CINAHL. Using the 'advanced search' option of these scientific databases, the latest search has been completed in January 2019. The commonly used keywords for literature search were- *Ageism, discrimination, stereotype, prejudice, dement*, Alzheimer Disease, Social care.* The main focus of the literature search was to comprehend the essence of original research in this newly emerged field. The search strategy followed a number of limits to identify the most relevant scientific journal articles.

- English only
- From Jan,1990-Dec,2018
- Scientific journal article (peer-reviewed full text)
- Exclude dissertations
- Original research article

Literature Report

Currently, the global estimated population aged 65 and over numbered 962 million is expected to be doubled by 2050 which will create an overburdened health-care delivery system. Moreover, elderly care covers the health and social care services for the people with dementia together with diversified service quality and delivery of care. From a global aspect, people with dementia are commonly excluded or ignored from the final decisions of care services for them. The decision-

making procedure has also been identified as a problem that assists in the progress of dementia. Most of the previous studies mainly focused on capacity assessment of people with cognitive impairments with a greater ignorance on the formal and legal contexts of these decisions. Additionally, most research related to the decisions on care services for people with dementia has focused on the perspectives of caregivers. This finding supports a previous research where it is argued that the engagement of people with dementia during the care negotiation (need assessment meeting) is significant and assists to reduce eventual anxieties. The previous research related to needs assessment meetings have focused on various aspects such as role of care managers in decision making or relatives of the older person like spouse, adult child get involved into the negotiation meeting. The 'type of involvement' might refers ageist attitude or a reflection of age-related stereotypical notions which need to be addressed properly. Thus, this project has an interest to investigate the needs assessment meeting to understand how age-related stereotypical notions might result in possible social exclusion (or inclusion) for the people with dementia in Sweden.

Conclusive Remark

The care for older people with dementia is attached with the social welfare system in Sweden and the entitlement to formal support follows a systematic procedure. Needs assessment meeting is the central part of the entitlement procedure where mostly the family or relatives of the client choose the preferred service. There might have influence of age-related stereotypical notions during the assessment and decision-making procedure which need to be explored through further research.

2.4 Wenqian Xu, ESR 10, Linköping University

A report on existing literature related to ageism as a barrier to provision of relevant support and services with a particular focus on *media and communal communication*

Literature Review Process

Since the present research subject focus on both media representations and media constructions of older people, the review was performed in two steps and endeavoured to gain comprehensive scientific knowledge of this domain.

Step 1: The review process was performed by interchangeably using a variety of keywords. Google Scholar was firstly employed to search most relevant and latest literature, using keywords of *media portrayal, media representation, ageism, age stereotypes, older adults/persons/individuals/people, elderly/elders.* The Web of Science was used to search literature published from 1975 to 2019, using the abovementioned keywords. Scientific articles were derived from the categories of Communication, Social Sciences Interdisciplinary, Sociology, Gerontology, Cultural Studies, and Social Issues.

Step 2: The review employed the keywords (including *Swedish authorities, new/social media use, and government/institutional communication*) to gain the knowledge of media practices within Sweden municipalities in the Web of Science.

Literature Report

The existing research on visual representations of older people suggests that

- Media representations of older people in Europe and North America have moved from visual under- and misrepresentation (mostly negative depictions) to more positive portrayals during the last decade of the 20th century. Conversely, mass media in East Asian cultures have been associated with older people (and later life) with negative notions. Yet, the existing research fails to explicate contemporary representations of older people are formed in Swedish media or the broader Nordic welfare context.
- Researchers have used content analysis techniques to investigate mass media representations of older people, especially focusing on television programs and print media. However, little is known about digital media representations of older people, for instance, Facebook.
- Much of the research on media representations of older people up to now has been descriptive in nature. The existing scientific works have not dealt with media construction of older people (and later life).

ESR 10's research focuses on Swedish authorities which have increasingly used social media and examines Facebook photos of older people produced by Swedish local authorities. Based on the identified research gaps, this research aims to investigate the following aspects:

- Media construction – how institutional routines of local authorities impact media representation of older people.
- Social media representation – what social media representations of older people are shown in Sweden. This can be further discussed concerning the Nordic welfare context.
- Methodological developments – how visual signs are used in media representation of older people. In particular, which signs, contexts and activities were shown.
- Theoretical developments of ageism – how social media logic contributes to the separation of old and young.

Conclusive Remark

The review identified three cores (local authorities, social media, and ageism) in existing literature. This research focuses on the overlapping area of three cores and contributes to the theoretical and methodological developments of the "visual ageism" concept.

2.5 Jovana Brkic, ESR 7, Charles University

A report on existing literature related to ageism as a barrier to provision of relevant support and services with a particular focus *on ageism in medication use*. Three literature reviews have been undertaken considering the topic ageism in medication use by ESR 7:

1. Ageism and age-blind approach in medication use in older patients (Published: Fialova D, Laffon B, Marinković V, Tasić L, Doró P, Sóos G, Mota J, Dogan S, Brkić J, Teixeira JP, Valdiglesias V. Medication use in older patients and age-blind approach: narrative literature review (insufficient evidence on the efficacy and safety of drugs in older age, frequent use of PIMs and polypharmacy, and underuse of highly beneficial nonpharmacological strategies. European journal of clinical pharmacology. 2019; 4:1-6.)
2. Prevalence of potentially inappropriate medication use among older adults in Central and Eastern European Countries (Preliminary results were presented: Brkic J, Fialová D, Reissigová J, Apostoli P, Bobrova V, Capiau A, Drzaic M, Grešáková S, Ince I, Grešáková S, Ozkan O, Puchon E, Sesto S, Tachkov K. Potentially Inappropriate Medication Use in Older Patients in 8 Central and Eastern Europe countries participating in the Horizon 2020 EUROAGEISM project: a narrative literature review. Abstract presented as an oral presentation and poster at the 48th European Society of Clinical Pharmacy Symposium "The Digital Revolution: Supporting clinical pharmacy through e-health, digital support systems, big data and more"; 2019 October 23-5; Ljubljana, Slovenia.)
3. Risk factors for potentially inappropriate medication use in older people residing in nursing homes (Preliminary results were presented: Brkic J, Fialova D, Gresakova S, Reissigova J. Systematic literature review on social, economic and healthcare provision-related risk factors for potentially inappropriate medication use in older patients. Abstract presented as a poster at the International Association of Gerontology and Geriatrics European Region Congress 2019; 2019 May 23-5; Gothenburg, Sweden.)

Objectives:

1. Description of the main barriers related to insufficient individualization of drug regimens associated with age-blind approaches, which results in ageist practices
2. Prevalence of potentially inappropriate medication (PIM) use among older adults in Central and Eastern European Countries (CEECs)
3. Risk factors for PIM use in older patients residing in nursing homes

Literature Review Process

1. PubMed, Web of Science, Embase, and Scopus databases were searched. The last search was done in October 2018. The focus of this narrative review was on scientific articles - mostly randomized controlled trials, but also observational studies and systematic or narrative literature reviews - published in peer review journals since 2000. The search strategy contained terms related to: ageism, inappropriate prescribing, inappropriate drug use, potentially inappropriate medications, aged, geriatric patients, older patients, frailty, randomized controlled trials, clinical trials, underrepresentation, observational study/studies, age-related changes, negative outcomes, positive impact, non-pharmacological methods, physical activity, and physical exercise. The search was limited to articles published in the English language.

2. A literature review was conducted using the following electronic databases: EMBASE and MEDLINE. We included original studies published as full-text articles that describe the prevalence of PIM use among older adults in CEECs. We excluded studies: 1) reporting the outcomes of interventions designed to reduce PIM use, 2) focusing on a specific group of patients, 3) focusing on specific medication/class of medications.
3. MEDLINE and EMBASE databases were searched to identify all articles published on risk factors for PIM use in older patients (aged 60 years or older). The electronic database search was supplemented with a manual search of included studies, reviews and PhD thesis. Original research studies published in English and as full papers were included. We excluded studies: measuring the prevalence of PIM use as an outcome of the intervention, focusing only on a specific patient group (e.g. palliative patients), disorder or medication class. The last search was in July 2019. We did not perform a meta-analysis due to differences between the studies in: designs, settings, metrics of outcome, and clinical heterogeneity.

Literature Report

1. Older people are underrepresented in clinical trials. In order to minimize ageism in medication prescribing for older people and improve older peoples´ health, the number of older people enrolled in clinical trials should be increased to have more evidence about the real efficacy and safety of medications in this age group. This issue is planned to be addressed by writing policy recommendations for EU and national regulatory bodies.
2. Results of this review showed that there is a lack of knowledge on the prevalence of PIM use in most of the CEECs – no studies were conducted in 5 of 16 CEECs, namely, Bulgaria, Estonia, Latvia, Montenegro, and North Macedonia. We plan to address this research gap in our comparative international study.
3. Existing literature explored a variety of risk factors for PIM use. In contrast to a considerably higher amount of literature on patient-related or clinical-related risk factors of PIM use, less evidence is available on social, economic and healthcare-related risk factors. Heterogeneity among the analyzed studies was high and thus the results of the studies could not be summarised meaningfully. This research gap we plan to address by conducting the international study that will enable us to draw conclusions regarding the risk factors for PIM use.

Conclusive Remark

We plan to deal with policy issues and identified research gaps by: writing policy recommendations and conducting the international study on prevalence and risk factors for PIM use in older adults in all settings of care.

3 Discussion

At the end of the process, discussion centred on the difficulties of conducting a search using the terms 'ageism' or agism' (English and American spellings) given the relatively recent coinage of the term (in 1969). Other considerations of search terms were discussed, such as the multitude of vocabulary associated with age and social inequality (e.g. age discrimination, age stereotype, age prejudice, and more). The work of Herbert Blumer was suggested to ESRs. Blumer (1971:299) wrote on the identification of social problems and stated that 'a social problem does not exist for a society unless it is recognized by that society to exist'. Given that ageism has been identified as a social problem, the definition is still fraught with difficulties and these have been addressed in an excellent paper by Bytheway and Johnson (1990). Discussions with the group centred on further words that may help to identify ageist practices and these included: Age discrimination; inequality, diversity, segregation, prejudice, age limits, attitudes to ageing.

4 Conclusion

The work produced by the ESRs shows the preliminary searches they have undertaken to explore literature related to ageism as a barrier to the provision of relevant support and services with a particular focus on social capital, health and social care services and also a barrier to appropriate and safe medication use. All ESRs found searching the term ageism challenging due to the implicit nature of ageism and due to the fact that ageism is a relatively new term and therefore not always stated in the literature.

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