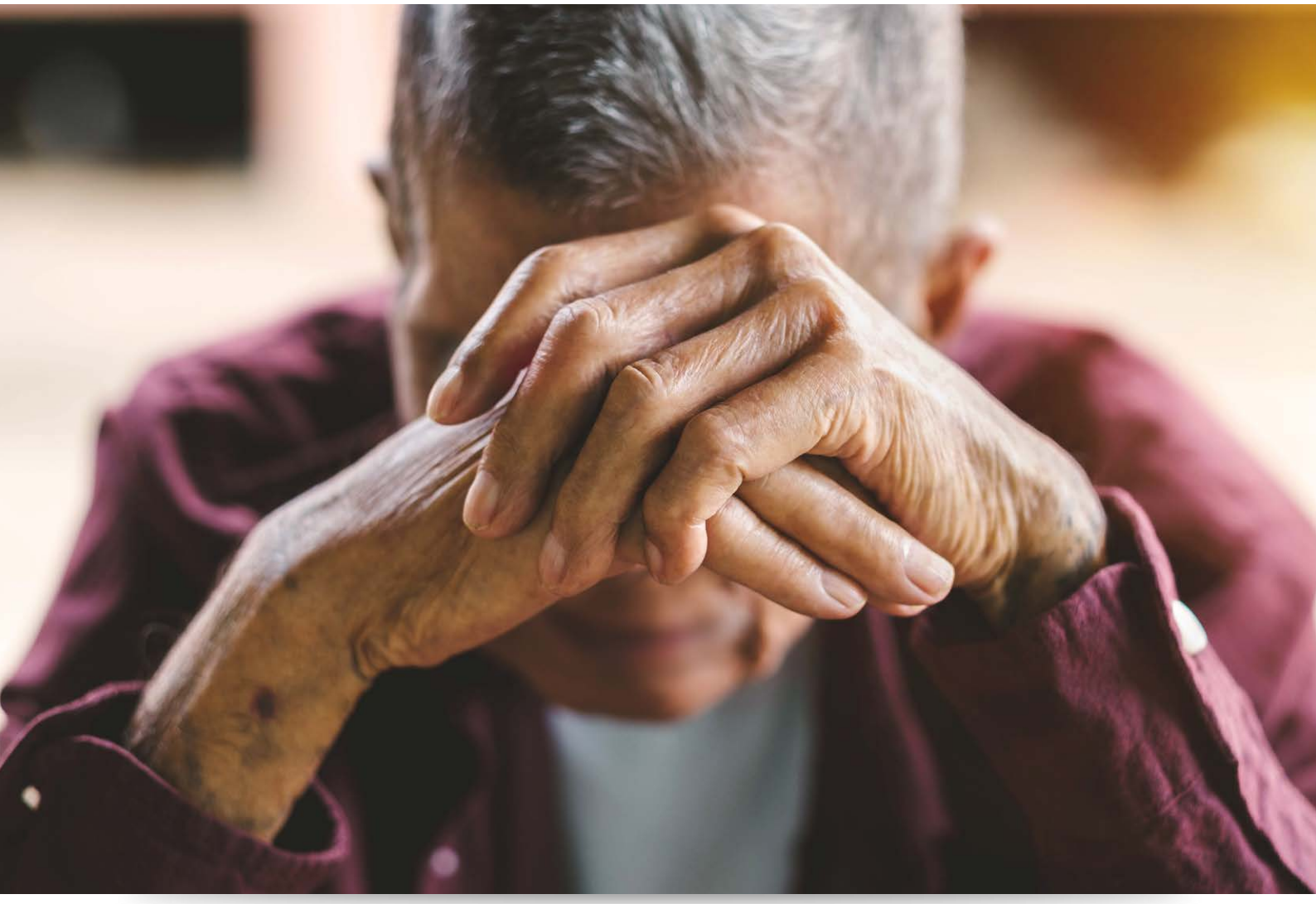
TABOOS AND PREJUDICES IN LONG-TERM CARE



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EUROPEAN AGEING NETWORK

July 2021

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TABOOS AND PREJUDICES IN LONG-TERM CARE

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Publisher:
Asociace poskytovatelů sociálních služeb České republiky
Vančurova 2904, 390 01 Tábor
Czech Republic
www.apsscr.cz

ISBN: 978-80-88361-16-9
ISBN: 978-80-88361-17-6 (online)

This publication was supported by JP1, s. r. o.,
Špidrova 47/42, 385 01 Vimperk, Czech Republic.

LIST OF CONTENTS

Preface 5

1. Goal of this report 8

1.1. Goal of this report 8

1.2. The working group 8

1.3. Selection of prejudices and taboos 9

1.4. Definition of a prejudice and taboo 12

1.5. The report 12

1.6. Working group discussions 13

1.7. Description of prejudices 14

1.8. Description of taboos 14

2. Prejudice: old people need protection, guidance and sometimes supervision 15

3. Prejudice: oldER people have no duties in society 21

4. Prejudice: old people/age have no value 23

5. Prejudice: the worthless fourth/final phase of life 27

6. Prejudice: the idealisation of living at home 31

7. Prejudice: care at home is always better and cheaper than residential care 34

8. Prejudice: the delusion of never-ending productivity 36

9. Prejudice: old people are not lonely per se, but may feel so personally 40

10. Prejudice: old people do not need a differentiation in housing, services and care 42

11. Prejudice: nursing homes have no privacy and lack of self-determination 45

12. Prejudice: people dependent on care need high educated professionals who take care of them 49

13. Prejudice: ageing is a disease 53

14. Prejudice: old people cannot handle technology 57

15. Prejudice: old people are not active anymore and cannot have fun 62

16. Taboo: elder abuse 65

17. Taboo: death is our arch enemy 72

18. Taboo: love among older people 74

19. Taboo: sexuality in old age 77

20. Future actions and pointers 87

PREFACE

We all face different taboos and prejudices during our whole life in all possible activities, segments, areas, environments. They appear and disappear and change with time; generally changing with our society and the world. This also applies to the long-term care sector.

It's my pleasure to introduce to you another key document of the European Ageing Network made by our members – experts from the long-term care sector.

It's a follow up document to the VISION 2030 for long-term care that we introduced at the end of 2019. You can find some of the taboos or prejudices in our VISION 2030 that we have identified as barriers for future and sustainable development of long-term care in the European countries. Creating a new working group with experts from 7 European countries who worked on describing the biggest taboos and prejudices was a logical consequence.

The more you talk about taboos and prejudices the less powerful they are. Sometimes the only reason we are facing them is because we are afraid or feel uncomfortable talking about them. Often, we lack all of the information.
This document was created to show the biggest taboos and prejudices, to open discussions, to bring the missing information and to break the taboos and prejudices.

We believe and hope that these open expert discussions will not only break or eliminate some of these taboos and prejudices, but could contribute to better care, higher quality of life for long-term care receivers and to better long-term care environments, improving how the sector is viewed.

We are happy for you to share, disseminate and use this document to benefit from it. Thank you for your work in caring for older people.

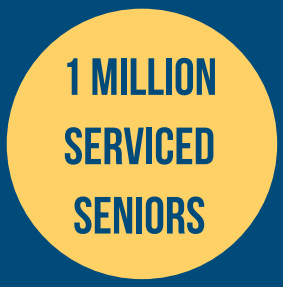
Jiří Horecký
President of the European
Ageing Network

EUROPEAN AGEING NETWORK

The European Ageing Network (EAN) groups **more than 10.000 care providers across the European continent.** Members represent all types of organizations and individuals active for older persons and all types of ownership including for profit, not-for-profit and governmental organizations. It is their vision and mission to improve the quality of life for older persons and support them in making each day a better day by providing high quality housing, services and care.

The European Ageing Network (EAN) is present in 25 European countries. With EAHSA well represented in Northwestern Europe and E.D.E. in the South-East, the combination makes of the European Ageing Network a truly pan-European organization. EAN does not stand alone in pursuing its vision, values and mission. It is affiliated with the Global Ageing Network (GAN), a global network with its office in Washington D.C. EAN and GAN bring together experts from around the world, lead education initiatives and provide a place for innovative ideas in senior care. They pave the way to improve best practices in elderly care so that older people everywhere can live healthier, stronger, more independent lives.

The members of the European Ageing Network (EAN) are servicing over 1 million older people in Europe. Longevity is one of the biggest achievements of modern societies. The Europeans live longer than ever before and this pattern is expected to continue due to unprecedented medical advances and improved standards of living. By 2020, a quarter of the Europeans will be over 60 years of age. Combined with low birth rates, this will require significant changes to the structure of European society, which will impact on our economy, social security and health care systems, the labor market and many other domains of our lives.



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As professionals we seek to improve the quality of care and supervision. Common training standards, reciprocal visits and observation, congresses and symposia all foster professionalism among care home directors and a greater understanding of the various forms of care and assistance. Creating humane living and working conditions in our homes is the vision we are all striving for in the EAN.

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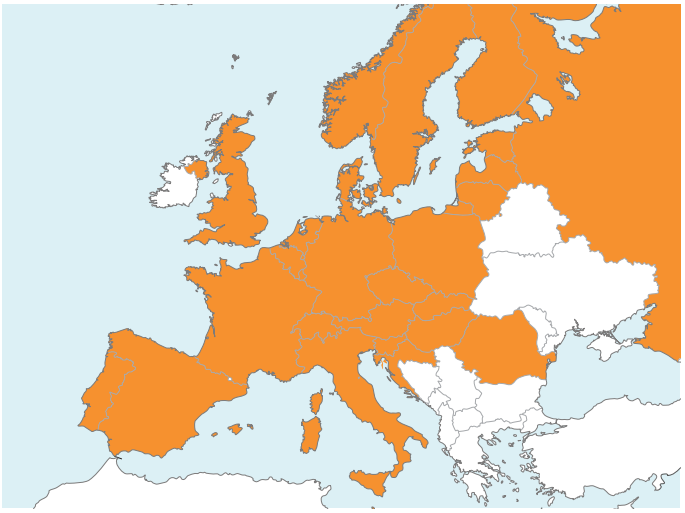

1 GOAL OF THIS REPORT

1.1. Goal of this report

Prejudices and taboos are everywhere in society. In an ageing population, more and more stereotyping of older people is taking place. A general term for this is ageism, used by Robert Neil Butler in 1969, to describe discrimination against the older population based on old age and the ageing process. The EAN has a sense that ageism is stuck being used in more general, not particularly concrete terms.

Therefore, the EAN has formed a working group of experts to give the EAN membership more insight about what prejudices and taboos exist about old people in the context of residential care facilities.

The goal of this report is to give the EAN members tools to deal with prejudices and taboos.

1.2. The working group

The working group is assigned by the EAN Board. It consists of highly qualified experts with strong experience in care and support of care for older people in residential and home care settings. All members are appointed in a personal capacity.

The members of the working group are:
Freek Lapré (Chairman)
Chairman ECREAS,
The Netherlands

Megan Davies
TRANS-SENIOR PhD Candidate
at Curaviva Schweiz and University of Basel, Switzerland

Jiří Horecký
President EAN, Czech Republic

Marcel Smeets
Policy Advisor EAN,
The Netherlands

Aad Koster
Vice-President EAN,
The Netherlands

Markus Mattersberger
CEO Lebensweltheim, Austria

Markus Leser
Director CuraViva, Switzerland

António Gouveia
CEO of Residências Montepio,
Portugal

A brief description of all members can be found in attachment 1. Secretarial support was given by Brigitte de Veld from the Netherlands.

1.3. Selection of prejudices and taboos

In 2019, the EAN sent a survey to their members and ask them what dogmas and taboos were dominant from their perspective as a care provider for older people.

This has led to a list full of characteristics that needed attention according to EAN members. The experts reviewed the list and selected topics that could be characterised as a prejudice or a taboo.

We also held a virtual workshop during the online LARES conference. With approximately 300 participants in the workshop we gained new insights into the topics that we were discussing in the working group.

From EAN and working group member input, we selected 19 issues for discussion.

Initially, we used the term dogma rather than prejudice, however during working group meetings we struggled with the definition of a dogma.

A dogma was, according to the working group, belief that is held unquestioned. It is rooted in a doctrine or religion. That is not helpful for a report that wants to clarify issues and to make them open for discussion. Therefore, we changed the term from dogma to prejudice.

Every member was challenged by another member who opposed the content of prejudice or taboo written by that working group member.

The order in which the prejudices and taboos are presented in this report do not reflect a certain priority.

1.4. Definition of a prejudice and taboo

In this report we make a distinction between prejudices and taboos.

There are different definitions of prejudices and taboos. We selected definitions that are aligned with the purpose of this report.

A prejudice is defined according Gordon Allport (1979) as „a feeling, favourable or unfavourable, toward a person or thing, prior to, or not based on, actual experience „.

It fits with the starting point of the working group: ageism which is defined as stereotyping older people.

A taboo is defined as "a subject, word or action that is avoided or forbidden for religious or social reasons" (Cambridge Advanced Learner's Dictionary and Thesaurus, 2021).

Therefore, compared to prejudices, taboos are more difficult to discuss since the subject is avoided or forbidden to talk about.

1.5. The report

This report reflects our discussions, and findings from the literature. We do not claim that the report is an academic piece of work, but where possible, we have supported content with literature references.

We also realise that this report is far from complete. Completion is not what we intended with this report, instead we believe that this report provides an opportunity to open discussions about prejudices and taboos surrounding the care and support of older people, particularly in residential and home care as well as those in society as a whole.

You may wonder why we did not involve residents and family members in developing this report. The working group of course supports this idea, but it is not the place of EAN.

Discussions intended to involve residents and family members must take place with local facilities and national associations, who can address prejudices and taboos on a more personal level and with cultural perspective.

This report is a live document that EAN members can continue to add their experiences and solutions to. It is not set in stone, but provides a starting point for discussions.

We distinguished 14 prejudices and 4 taboos from issues collected by EAN membership.

The format to describe prejudices and taboos is as follows:
- Description
- Fact checks
- Conclusions
- Recommendations for the EAN members.

Occasionally, political reasons made it difficult or even impossible to make recommendations. For this reason, some prejudices and taboos lack recommendations.

The report ends with future actions and pointers for EAN members.

1.6. Working group discussions

The working group met several times in Prague and Vienna in the pre-corona era and once in Zürich in 2020. All other meetings in 2020 and 2021 were online.

All members were very much involved in the conversation. Our discussions were passionate, sometimes emotional, but also rational and fuelled by real-life situations, videos and literature.

All members have contributed to this report using their own background and experiences.

1.7. Description of prejudices

The working group selected the following prejudices to discuss and work out in this report:

- Old people need protection, guidance and sometimes supervision
- Old people have no duties in society.
- Old people/age have no value
- The worthless fourth/final phase of life
- The idealisation of living at home
- Care at home is always better and cheaper than residential care
- The delusion of never-ending productivity/Old people are unproductive
- Old people are lonely perse, but may feel so personally
- Old people do not need a differentiation in housing, services and care
- Nursing homes have no privacy and lack of self-determination
- People dependent on care need high educated professionals who take care of them
- Ageing is a disease
- Old people cannot handle technology
- Old people are not active anymore and cannot have fun.

1.8. Description of taboos

The working group has selected the following prejudices to discuss and work out in this report:

- Elder abuse
- Death is our arch enemy
- Love among older people
- Sexuality in old age.

2 PREJUDICE: OLD PEOPLE NEED PROTECTION, GUIDANCE AND SOMETIMES SUPERVISION

By Markus Mattersberger & Jiří Horecký

2.1. Overview

Protection, guidance and supervision - three subject areas that should not only be seen in terms of a care mandate, but which more or less intervene in the self-determination and autonomy of older people. With the prejudice that older people need protection, guidance and sometimes even supervision, the individuality of older people is faded out and it is generally assumed that they cannot take care of themselves. How can this assumption be explained?

All our lives we are being put at risk and we accept what is called admissible risks yet with groups of people we call vulnerable we may proceed with different approaches. Generally, in long-term care providing care for older people, the care providers are trying to avoid their users from all potential risks that could cause them any harm, injury or damage.

This assessment may be particularly obvious for residents in care facilities, so there is usually a certain reason why risks are removed in a nursing facility. In most cases, a move to long-term care happens when it is no longer possible to live in one's own four walls - i.e. when the older person is no longer able to care for themselves alone or even with support, either because of a physical or cognitive decline. Often, however, such a move is also based on the person feeling unsafe: what happens if I fall at home? On one hand, a real need for protection, guidance and, in some cases, supervision can be derived from this, substantiated by care diagnoses

and thus make concrete measures necessary; although these require professional reflection in their interpretation and form. It is therefore understandable that appropriate guidance is needed, for example to regain skills that have already been forgotten. A goal is needed both at home and in the nursing facility to reach a higher degree of self-determination and autonomy. However, excessive instruction limits the possibility for self-determination and autonomy. Here the boundaries are fluid and require constant reflection of professional action - the individual situation of the older person concerned must be addressed and the nursing professional's actions adapted.

Aside from the professional nursing view, in most cases there is also a legal component to consider (https://dejure.org/gesetze/BGB/832.html. This imposes corresponding supervisory duties on the carer, the violation of which can have consequences under both criminal and civil law (see: https://dejure.org/gesetze/BGB/832.html). In other words, it is also a matter of legal security for the carer. The right of self-determination and the need for protection against self-endangerment or endangerment of others are repeatedly mentioned in conjunction. According to Borutta, for example, the carer must weigh up the duty of care against the resident's right to self-determination in each individual case (Borutta, 2000, p. 105).

With regard to nursing homes, this assessment is reinforced by at least two further aspects. On one hand, the critical view of society and the media of services provided in care facilities and on the other hand, the resulting willingness of those responsible to make the quality of services provided visible and measurable.

The critical view of society and the media on care facilities means that, if possible, any negative development or scandal should be avoided, or at least not be externally visable. The latter aspect in particular promotes a negative culture of error, and in many cases an overflowing bureaucracy is established in order to make provisions for all eventualities and incidents. This procedure is understandable in that the nursing staff or facility managers are

usually held responsible for undesirable developments or scandals. Klie (2019) also holds society partly responsible, writing that a scandal in a nursing facility always shines a light on the community, the civilian population (p.119). Leser (2017) writes about the fact that one must abandon the idea that every eventuality can be prevented by a set of rules (p. 172). In any case, it becomes understandable that measures and actions also serve the nursing and care personnel's own legal security, rather than only improving the living situation for older people in the facilities. In other words, everything is done and every action is argued accordingly to ensure the best possible protection and avoid neglect, even if self-determination and autonomy may suffer as a result.

In order to make the services transparent, comprehensible and in a certain way reproducible, quality systems have gained a foothold in many care facilities. The aim was and still is to prove which measures used minimized risks and which improved performance. KLIE writes: „The entire quality assurance machinery has never been primarily people-oriented, but always risk-oriented: Liability claims are to be excluded, admissions to markets secured, and cost-efficient management of operations ensured" (Klie, 2019, p. 80). The intention is not to deny the usefulness of quality management systems, but to focus on what nursing and care staff in the facilities are striving for - an appropriate quality of life for the older people. It is not primarily a matter of demonstrating that falls, pressure ulcers or urinary tract infections could be avoided by appropriate measures, but rather that an appropriate level of quality of life could be achieved by preventing them. There is nothing wrong with quality assurance to increase efficiency and liability, said LESER, but the older person must be considered, otherwise quality assurance becomes an end in itself and becomes meaningless for those in need of care and dependent people (Leser, 2017, p. 174).

In long-term care facilities, particularly during the SARS-CoV-2 pandemic, we have been encountering another approach that is usually typical in most European countries. We have been focussing on the protection of physical health above all

rather than seeing the immediate and long-term impact on the mental health of older people.

The central governments were concentrating on avoiding infections rather than considering the damage to mental and social health caused by total isolation.

This prejudice is also linked with the idea of an ideal life in a nursing home. Although we are living our whole lives in millions of different ways (some healthy, some not, some safe, some risky) society has provided an ideal end of life model of protection.

Examples:

- Restrictions on going out (during worse weather conditions) vs. the freedom of going accepting all the risks.
- Diet restrictions while having diabetes vs. the freedom of eating not recommended meals, deserts (when life is not in danger).
- Restriction during any flu pandemic vs. the right to see family members.

2.2. Conclusions

This prejudice is reinforced by the fact that older people are coming to care facilities later and later, with an increasing need for support. Nevertheless, the topics of self-determination and autonomy must be increasingly included in professional discourse; although a social consensus is also needed on how to deal with the consequences and risks of lived autonomy and self-determination. Self-determination requires self-responsibility and the effects must be borne jointly by society. The frequently practiced approach of demanding self-determination, but leaving the responsibility for corresponding risks and consequences to care staff hinders the desired development.

Although we accept risks throughout our whole lives and decide what are admissible and acceptable risks for us, towards the end of life this is guided by the system and prejudices, with many people claiming that older people should be restricted to avoid risks.

Being old does not equate to a loss of capability to make decisions, reduced accountability or ability to accept risks. We should and must allow calculated risk even at the end stages of life.

2.3. Recommendations for EAN members

The most important thing to abolish prejudices is to talk about them in a broad dialogue. EAN members should therefore very actively engage in broad discussions with residents, their relatives, those responsible for the facilities and also residents' representatives and politicians on precisely these issues, which are concerned with the dignity, self-determination and autonomy of older people.

Political decision-makers, in particular, must be aware of the implications of the greatest possible legal repercussion for nursing and care staff. For their part too, a corresponding awareness in society must be strived for and promoted by addressing these issues. Self-determination also means self-responsibility. Images that generate a fully comprehensive mentality must be corrected, even if their political marketing may be very attractive.

References:

Borutta, M. (2000). Pflege zwischen Schutz und Freiheit, Das Selbstbestimmungsrecht verwirrter alter Menschen, Hannover, Deutschland, Vincentz GmbH.

Leser, M. (2017). Herausforderung Alter, Plädoyer für ein selbstbestimmtes Leben, Stuttgart, Deutschland, Kohlhammer.

Klie, T. (2019). Wen kümmern die Alten? Auf dem Weg zu einer sorgenden Gesellschaft, München, Deutschland, Droemer

European Ageing Network. (2020). Long term care for elderly – 12 key statements on COVID 19 reflections Retrieved from European Ageing Network website: https://www.ean.care/media/fileman/FINAL_STATEMENTS_EAN_GAN_COVID_1.pdf

Kiyota, E. (2021). Elder care providers & COVID-19, Cross cultural perspectives, Global Ageing Network, Retrieved from Global Ageing website: https://globalageing.org/wp-content/uploads/2021/02/Global-Ageing-Network-COVID-19-Research-Report.pdf

3 PREJUDICE: OLDER PEOPLE HAVE NO DUTIES IN SOCIETY

By Jiří Horecký

3.1. Overview

Sometimes older people are divided in accordance with economic activities - either working or retired. The line can be drawn between two phases of life, first is the period at which people who work pay the state in various ways, such as taxes, social security insurance payments or health care insurance payments. The second period is following retirement thus economically inactive older people are being paid by the state through pensions, social security payments and/or care allowance and benefits. This provision from society is occasionally linked with the feeling that older people have no more duties in society.

Older people have played their part in economic activity and they should rest now without being bothered. However, the reality should be and is different. All people have duties in society regardless of age. They can and therefore should contribute to society with their knowledge and experience.

It's also about new social roles while aging.

Studies undertaken in care homes show that older adults need to feel like a valuable member of society, which contributes to quality of life. This includes still being trusted to complete tasks for themselves, and help others. In addition, it should be recognised that in many cultures, grandparents act as childcare for the newest generations, enabling

parents to continue to work and contribute economically to society themselves. Volunteer work is also common following retirement, not to mention caring for a spouse, which reduces need for societal resources.

Furthermore, family obligations incorporate not only caring for a partner but also caring for a parent or parent-in-law as a result of the increasing longevity of the oldest old.

3.2. Conclusions

This prejudice is linked very closely with another – having or not having duties in society is also about being a part of the society, therefore being a benefit, not a burden in society.

3.3. Recommendations for EAN members

The most effective way to break prejudices is to openly talk about them and to show their inaccuracies.

In other words, promote practical examples of older people still being an active part of society, for example volunteers among seniors, and be proactive in opening discussions about older people and their duties in society.

References:

Vidovićová, L. (2018) New Roles for Older People. Population Ageing, 11, 1–6 . https://doi.org/10.1007/s12062-017-9217-z

Wija, P.,& Vidovicova, L. (2015), Working longevity, Prague, Konfederace Zaměstnavatelských a Podnikatelských Svazů ČR.

4 PREJUDICE: OLD PEOPLE/AGE HAVE NO VALUE

By Jiří Horecký

4.1. Overview

In traditional societies and community groups, old people are treated and seen with respect as important "advisors" and as people who continue traditions and impart wisdom, knowledge. In every part of our lives we are receiving and giving; receiving care while children, sick or old and giving our time and energy while working or providing care.

With the demographic prognoses and expert discussions surrounding the sustainability of long-term care, older people are often seen or mentioned as a burden - economic burden, bulk of care, sustainability of pension systems, etc.

By value, we mean the amount of money we get for goods and services; but life cannot be exchanged or converted to monetary value. While we determine the value of life, we must, where possible, deal with ethical concepts and dilemmas rather than economic principles and approaches. In practice, we encounter a simple approach that de facto determines the value of life according to how much time we have left. The same logic was applied by some European hospitals during the Covid-19 pandemic. Although we rely on an economic approach when discussing or determining the value of life, human life is priceless for its vicinity and for its loved ones. If someone close to us dies, we would give or more precisely sacrifice a lot so that we can return or prolong their life for a

while. The pain and suffering experienced by loved ones and survivors is priceless.

When thinking about the value of life, two great ethical concepts often clash - the utility theory and the theory of moral categories. According to the utility theory (Jeremy Bentham, 18th century, England), a moral solution is the one that maximizes the utility of an act. Each utility can be quantified, meaning that calculating the value of the expected economic activity or similar parameters of a human is justified. In theories of moral categories, life is assigned the highest value. For example, in John Locke's Moral Philosophy, the right to life is inalienable and one cannot give it up even by consent, unlike the other two fundamental rights which are freedom and property. In practice, it would be good to ask which purposes we consider for value of life. If this is, for example, for insurance purposes, then an economic justification is appropriate. If the right to health care is decided in a multi--individual situation, then other values should be included, such as the question: „For how many people will the death of this person be an irreplaceable loss?" Decision-making should never be mechanically based on one simple principle such as the patient's age.

4.2. Conclusions

There are extraordinary situations where a person or community is forced to choose between human lives. In some situations, such as a sinking ship, people make their decisions according to established patterns based on certain generally accepted values tested by history. For example, children are saved first, then women as child bearers for the future of the human race. However, there are other patterns that suggest the weakest and most vulnerable should be saved first because, unlike the strong, they are less able to save themselves. In both models, the moral code respecting human life is applied and in both, on this basis, a rational reflection on the consequence of the decision is manifested. It can be seen that in real life, the two theories do not have to oppose each other.

If readers of this article expect a final resolution, a clear statement of what is actually right, they will be disappointed. This question does not have a clear, or even correct answer. It is more a question of values. Everyone perceives this differently. Readers under the age of 40 are very likely to identify more with the horizontal concept (we could perceive a vertical curve as the time we have left and the horizontal curve as all the work and achievement we have done and brought tot he society during our life). Likewise, perhaps pragmatists or people oriented to „survival" would also identify with this. Older people, the age group of 45+, perhaps more likely 50+, will be more aware of the vertical concept and fully and absolutely rightly expect to consider and reflect on everything they have done for society, they are doing, and will still be doing.

In 1983, the President of the United States, Ronald Reagan wrote: „The real question is not when human life begins, but what the value of human life is."

We determine this value ourselves regardless of the formula that someone uses to appraise our lives, including for our own lives.

Let us not perceive and judge the value of human life solely on the basis of what one can or cannot do. Let us be not only generous in our judgments, but also wise, and let us judge human life from a retrospective point of view, that is, with respect for everything that a person has done for others in their life.

There are not so many discussions about the value of age and value of older people, but the key and crucial question is whether they should be discussed so much. Whether such discussion is needed or if they can contribute in a good and right development for our society to be better in the future.

Why should we discuss the value of human life and/or the value of any other human being regardless of their age? The courts are working with the value of human life in court cases to compensate victims or survivors.

We should certainly avoid and stop discussions about the value of life in relation of age and age phases. Every human being has priceless value and unlimited potential regardless of the circumstances.

4.3. Recommendations for EAN members:

We should have discussions about how to make our lives more valuable as a whole. More valuable working for society, other people, vulnerable people, those in need etc. in every age phase of our lives.

References:

Horecký, J. (2020), The Value of Human Life, In: EURO No. 32,33/2020, ISSN 1212-3129 and In Social Services No. 11/2020, ISSN1805–6857.

Horecký, J., (2020)The Right for your own Death, In EURO No. 43/2020, ISSN 1212-3129.

Visnovsky, E., (2017) On the value of human life, Ethics and bioethics, 7, 85-95, doi: 10.1515/ebce-2017-0003

5 PREJUDICE: THE WORTHLESS FOURTH/FINAL PHASE OF LIFE

By Megan Davies & Markus Leser

5.1. Overview

In many countries, old-age policy is fiscal policy. As soon as people become very old and vulnerable, any investment by the state is no longer seen as worthwhile. With each passing year towards death, very old people then become a cost burden for society. A fundamental social attitude like this robs the older people of their dignity. In political and social discussions, old age is still considered synonymous with illness. Old age is not a disease, but another phase of life.

It is common for society to associate old age with the 'final' phase of life, due to the assumption that older adults will become fully dependent. This is because when people discuss older adults, they tend to focus on care – whether it be care at home or moving into long-term care. This results in a focus on cost implications and potential burden on resources. This has been increasingly evident during the COVID-19 pandemic, where in some cases, the older population were prompted to deny themselves of resources in favour of the younger population, regardless of health status.

Biologists separate life into three phases: development, ageing and late life, and a growing body of research now suggests that there is a fourth phase immediately preceding death that scientists have called the „death spiral". In this respect, the fourth, or 'final' phase of life would therefore begin during palliative care; although at what stage does palliative care truly be-

gin? According to literature it occurs simultaneously to other care/medical care, but in an attempt to improve quality of life as the main goal as well as support for the person and their family (Morrison et al., 2004). Therefore, this could occur from the moment an older person moves into long-term care, or for a large percentage of their time living independently. In some cultures, this phase of life is considered the final phase before 'paradise', so regardless of monetary value attached, this phase is valued and therefore not considered worthless.

Ordinarily, healthy older adults are sought after in society. They can provide care to spouses and grandchildren. However, this still equates to usefulness being associated with either financial gain or providing a service. Older adults living with physical or cognitive decline quickly become viewed as a drain on resources, particularly when additional care is required. However, even in the 'final' phases of life when care is required, a person remains a valuable member of society. In addition, the way this fourth phase of life is lived should come down to the choice of the individual. They may wish to continue actively in a community, either in a care setting, the wider community, or both; or they may wish to rest having already given much of their life to the wider society. We need to consider that a phase of life can be lived without 'value' or 'worth' being attributed to it, simply because it is part of the lifecycle; which prevents any phase being considered 'worthless'.

5.2. Conclusions

As a society, we should appreciate the older population not only for what they do/have contributed to society, but in a way that simply respects the phase of life they are living in. No phase of life should be valued depending on financial gain, but should be valued because it is human life. We have an obligation to provide and care for the older population in the same way that they have for others throughout their lives, and need to stop associating this with burden.

There needs to be societal and political recognition that we live in a society for all, and not just in an

economically dominated meritocracy that is fixated solely on the achievements of today and tomorrow. Past achievements, attributable particularly to the older generation, need to be recognised and valued.

5.3. Recommendations for EAN members

We need to alter the way we discuss and view the older population, which includes seeing a person as a whole and not simply in a single phase of life as well as seeing each phase of life as valuable in its own right. Those who are lucky, will eventually reach old age and we need to stop viewing this as something to fear. Even when the need for care increases and long-term care sought, a person remains a member of a community and simply by being present in that space, contributes to it. If we start seeing older adults as their whole life, rather than the phase they are currently living in, we can benefit from their knowledge and overall contributions now and in the past. This should hold importance over financial value. We need to recycle this knowledge for current gain, while respecting the fourth phase for what it is – an inevitable part of a lifecycle.

References:

Morrison, R. S., & Meier, D. E. (2004). Palliative care. New England Journal of Medicine, 350(25), 2582-2590.

6 PREJUDICE: THE IDEALISATION OF LIVING AT HOME

By Megan Davies & Markus Leser

6.1. Overview

It is generally assumed that the older population has no desire to move into a long-term care and that they would prefer to live independently for as long as possible. While this might be the case for some, it is important to note that there are also people who are living with comorbidities or perhaps in isolation who welcome the idea moving into a care home. Furthermore, prolonging independent living following signs of comorbidities can lead to increased frailty and advanced progressive illnesses or multi-morbidities by the time a move into care does occur; which could reduce quality of life in older adults following admission (Hockley et al, 2016; Leichsenring, 2004).

There is an expectation that family members, including spouses who may also be living with some functional decline as a result of old age should 'step-up' and care for their relative (more so in some cultures than others). This is not always an ideal situation for the person receiving care, or the person providing care. This can cause a strain on relationships and cause a level of burden on the caregiver and guilt on the care receiver. In addition, changes in healthcare and social trends, such as reduced informal support from families due to increased economic migration and participation in the labour market by women in recent years reduces the possibility of care at home in later life (Leichsenring, 2004).

An article in the Schweiz am Sonntag on 23.12.2017 begins with the following sentence: „Unnecessary stays in nursing homes mean high costs for the general public and suffering for those affected". Such and similar statements are common in the media. Each time, the sentiment is one of direct opposites: „the nursing home is the bad option" vs. „the enjoyable and good life in one's own home", causing negative connotations associated with long-term care.

Continuing to live in one's own home is therefore idealised and romanticised, while care homes are feared and cause uncertainty. But this "black or white logic" is of no benefit to older people.

It is true that long-term care causes an additional transition at a potentially challenging time of life, but recently there has been a culture change in long-term care and there is more emphasis on autonomous living and person-centred care than has previously been seen (World Health Organisation, 2015). This focus on resident wellbeing and quality of life rather than only physical care creates more of a home environment for the older person, reducing the gap between independent living and a move into long-term care (Nolan, 2001).

6.2. Conclusions

The wants and needs of the older population in terms of living situation should be looked at on a case-by-case basis rather than the assumption being that remaining in independent living is what is best, or most wanted by all. In addition, the focus should be more on reducing the negative connotations associated with long-term care, rather than continuing to push the agenda of remaining at home. There needs to be a balance in resources to ensure home care and long-term care decisions are made for the right and best reasons for the individual and their family.

We need to reduce this „black or white characterisation" and work towards dealing with old age without fear. Wherever shortcomings exist in long-term care (and they certainly exist), they must be identified, discussed and rectified. We also need to highlight the problems

that exist within family settings at home. Living and care arrangements for older people must not be played off against each other. They represent complementary options; the choice will depend on the personal circumstances of each individual.

The saying that „older people want to live at home as long as possible" is of little use. While this desire is more than understandable, it must be understood that a move to long-term care could be a need rather than want and the best outcome for an individual depending on circumstance

In addition, it is not the wish of every older person to continue living at home receiving care from family members. We must be careful not to generalise and to treat each person as an individual.

6.3. Recommendations for EAN members

It is important to understanding shortcomings in care, which is usually the cause for reluctance to move into long-term care. It is also important to understand what support the older population has when living in the community, if this support is adequate, and if it could put others in the household at risk of burden – for example spouses

References:

Hockley, J., Harrison, J. K., Watson, J., Randall, M., & Murray, S. (2017). Fixing the broken image of care homes, could a 'care home innovation centre' be the answer? Age and ageing, 46(2), 175-178.

Leichsenring, K. (2004). Developing integrated health and social care services for older persons in Europe. International journal of integrated care, 4(3).

Nolan, M. (2001). Successful ageing: keeping the 'person' in person-centred care. British Journal of Nursing, 10(7), 450-454. doi:10.12968/bjon.2001.10.7.5330

World Health Organization. (2015). World report on ageing and health. World Health Organization.

7 PREJUDICE: CARE AT HOME IS ALWAYS BETTER AND CHEAPER THAN RESIDENTIAL CARE

By Marcel Smeets

7.1. Overview

Many politicians promote independent living, eventually with care at home, as better for both older people as well as for state budgets. In this conception residential care equals high costs, and home care is relatively cheap.

However, there appears to be very little published research on the costs and benefits of independent living, eventually in combination with home care, and how this relates to residential care. What is clear is that the cost of care depends on several factors: the type of care being received, location, and the type of care chosen (e.g. residential, home care or sheltered accommodation). Costs also depend on what sort of care is needed, how many hours of care are needed and the time of the day/week care is needed. For example, weekends may cost more and bank holidays up to twice the usual rate. Depending on circumstances, formal care could be combined with/supplemented by informal support from relatives and friends. Although this may differ if the care receiver is living with dementia, for example. In this case, much more care and attention might be required, which could become extremely costly.

Another difficulty when comparing costs and benefits are the "fundamental problems with quantifying benefits, in particular, when they relate to improvements in quality of life or physical and emotional well-being". In other words, researchers are struggling with at-

tributing values to qualitative costs and benefits. Additionally, what is the value and worth of always having trained staff on hand? Does this means you might feel more safe and secure? Is there value to not having to worry about utility bills, meals and household chores? Is there value in always having company and someone to talk to as well as having organised activities? What financial value is there of safe and adapted shelters for older people living with dementia?

Two Dutch studies suggested to stop silo-thinking in care for the older population and to consider care as a holistic matter – no matter where the care is delivered and how it is financed. A mixed-model of institutional care delivered at home could lead to higher quality of life for older people, higher work satisfaction for carers and societal advantages in efficiency and efficacy, therefore lower costs. Specific support of informal carers combined with professional care is proven to increase quality of life of people living with dementia and family members and maintain the required quality of care. This delays a move to long-term care by 8 months and significantly reduces costs (€ 40.000) per client during the whole process (De Berk. V., Van de Camp. L., Jongebreur. W., Reiff. E., Jongerius. M., 2021).

7.2. Conclusions

Care at home or in a residential setting is not a matter of economic or political choice, but should answer real needs. Depending of circumstances and means, the choice between care at home or long-term care should be a choice for older people themselves and/or their relatives and carers. Instead of considering care at home or long-term care as opposites, a mix of both worlds seems to be more satisfying, effective and efficacious.

7.3. Recommendations

EAN members could launch or stimulate a survey and analyses of costs (home care vs residential care) and also suitability (staying at home vs entering residential facility) and finding out the reasons why the residents are entering nursing homes.

8 PREJUDICE: THE DELUSION OF NEVER-ENDING PRODUCTIVITY

By Megan Davies & Markus Leser

8.1. Overview

There is an expectation that everyone should, and wishes to remain productive throughout their entire lives, and that the point at which productivity ends is when life is ending. This is partially a result of an achievement focussed society, which believes that everyone must contribute to remain of value. This outlook fails to see people as individuals, which we must do with the older population. We must look at older people as a whole person, which includes contributions made earlier in life, as well as what they can offer now.

Productivity changes throughout life and realistically on a daily basis. No one can maintain the same levels of productivity every day, and the older population is no exception. Even things that seem small, such as sharing knowledge, or living in a community holds with it a level of productivity, which should be valued as much as past achievements that might, in comparison, seem much larger. Ageing is associated with declining muscle mass, strength, power, and physical performance. This stereotype is often highlighted by media and the movie industry showing heroes as young and strong and older people as fragile, but wise. Within these roles, it is strength that ultimately wins battles, even when wisdom is what provided solutions.

In fact, there is just a minority of professions where physical decline impacts performance, and sometimes just partly. Among those pro-

References:

De Berk. V., Van de Camp. L., Jongebreur. W., Reiff. E., Jongerius. M., (2021), Domein-overstijgend samenwerken in de praktijk, eindrapportage monitoring & evaluatie,, Utrecht Netherlands: Significant Public.

fessions are, for example, miners, sportsmen/women, soldiers, etc. Sometimes they are able to continue their career as supervisors, teachers or mentors. In most professions, older workers may have less physical ability, but their experience and knowledge can prevent wrong decisions from being made. Not only do older employees hold more experience, but they tend to stay in jobs longer, have fewer days off and have a strong work ethic. In addition, their knowledge plays a critical part in training new employees. A diverse team structure provides a base for an effective work environment.

Aside from paid employment, the older population living in the community might also care for grandchildren, or volunteer within the local community, which is not only productive, but extremely useful in society. Productivity and usefulness go beyond monetary value. An older person living in long-term care may sit on the resident committee, volunteer in the home, or simply converse with other residents, making them feel less alone. This is still valuable and productive.

8.2. Conclusion

An expectation of endless productivity at the same level throughout life is not healthy and puts pressure on an already burdened society. Furthermore, a stereotype that loss of strength equates to less productivity is only relevant within specific roles in society.

Older people wish to and can be productive if they are allowed to be in a way that suits them. It is society's view of productivity that should be adjusted. In a society where, old age is inevitable (if we are lucky), we have a duty to provide and care for the older population respectfully.

It is important to reduce the pressure we put on people to be continually productive, and to alter our thinking of what productivity is. Productivity can be as simple as being part of a community (in the case of long-term care), or making a meal (in the case of independent living). We need to manage this expectation of productivity, which should be seen every day of a person's life.

8.3. Recommendations for EAN members

The EAN should launch a joint campaign with older citizens' associations and draw attention to the taboos on and about old age. CURAVIVA Switzerland has already put forward a proposal for such an initiative. This proposal is reiterated here:

Create an artwork together
3 persons from each EAN member state come together for one week (one resident, one staff member, one relative) and create an artwork: taboos of ageing (working title)

For this action we have to find financial support (that should be possible, idea: search for sponsors, maybe each country one, or a big international company – we are not talking about millions……)

Installation of this artwork somewhere in the world.

9 PREJUDICE: OLD PEOPLE ARE NOT LONELY PER SE, BUT MAY FEEL SO PERSONALLY

By Marcel Smeets

9.1. Overview

In public debate and the media, it is suggested that there is currently a "loneliness epidemic" in Western societies. Older people are seen as especially vulnerable to loneliness and social isolation, which can have a serious effect on their health. This prejudice has been more prominent during the COVID-19 crisis.

Older people may live alone, however many of them are not lonely or socially isolated. At the same time, some people feel lonely despite being surrounded by family and friends. A key (scientific) question is whether social isolation and loneliness are two independent processes affecting health differently, or whether loneliness provides a pathway for social isolation to affect health.

Being alone and loneliness are different, but related. Social isolation is the objective physical separation from other people (living alone), while loneliness is the subjective, distressed feeling of being alone or separated. It is possible to feel lonely while among other people, and you can be alone but not feel lonely. Social isolation and loneliness do not always go hand-in-hand. About 28% of older adults in the United States, or 13.8 million people, live alone, according to a report by the Administration for Community Liv-

ing's Administration on Aging of the U.S. Department of Health and Human Services; however, many of them are not lonely or socially isolated.

Using data from twin studies, researchers found that both social isolation and loneliness are independent risk factors and that genetic risk of loneliness significantly predicted the presentation of cardiovascular, psychiatric (major depressive disorders), and metabolic traits. Family history does not strongly influence this effect. Studies have estimated the heritability of loneliness between 37 percent and 55 percent using twins and family-based approaches. Also, a higher percentage of women than men report feeling lonely some of the time or often.

9.2. Conclusions

There is no evidence of a "loneliness epidemic" among later-born cohorts of older adults relative to earlier-born cohorts. Also, mastery and self-efficacy are crucial to fully understanding loneliness in today's society.

10 PREJUDICE: OLD PEOPLE DO NOT NEED A DIFFERENTIATION IN HOUSING, SERVICES AND CARE

By Marcel Smeets

10.1. Overview

According to literature, major components of good life quality in old age are broadly similar to those of general adult populations; such as good subjective physical and mental health, emotional wellbeing, sufficient financial resources, satisfying social relationships, social activity and a good living environment.

A number of factors can contribute to an older adult's quality of life, many of which relate to the surrounding environment. The four aspects of quality of life that most research looked at were social, physical, psychological, and environmental. Environmental includes financial resources, safety, health and social services, living environment, opportunities to acquire new skills and knowledge, recreation, general environment (noise, air pollution, etc.), and transportation. Environmental factors potentially impacting quality of life scores that were examined were housing (comfort, size, overall satisfaction with living space, etc.), facilities, residents (interactions with neighbours and neighbour behaviour etc.), nuisance (vandalism, crime, social insecurity etc.), neighbourhood, smell/noise and traffic. Unsurprisingly, all environmental factors examined were shown to impact environmental quality of life scores.

Taken together, these factors accounted for 24% of the variance in environmental quality of life scores, with facilities having the greatest

effect on scores. The next factor most impacting quality of life was psychological. Here, environmental factors accounted for 11% of variation, but only two of environmental factors were statistically associated with the effect on psychological quality of life (housing and residents). Just over 9% of physical health quality of life scores were accounted for by environmental factors.

The living environment has therefore had a direct impact on health via exposure to environmental factors, as well as indirectly impacting health. A healthy living environment includes pleasant surroundings in which healthy choices are easy. A healthy living environment not only encourages residents to be physically active and meet people, but also has plenty of green space and water, good air quality, and little noise. In a healthy living environment, people feel comfortable and safe.

Differentiation in housing, care and services for older persons is therefore more than just different numbers of square meters per person. For residents in long-term care, it is especially difficult to meet all of the different needs, requirements and demands – unless money and common values don't count. In most societies' general principles of solidarity, equality and equity make it difficult to accept that some well-off older people live in bigger, nicer, greener or "healthier" environments than the less fortunate.

Yet another way of differentiating housing, care and services is by aligning with the specific needs of a group of older people. Obviously, older people have different needs than those who are younger and/or more mobile, but within the broad group of older people, there are also sub-groups. Older people living with dementia generally need an adapted environment, but what is needed for other groups?

Differentiation is a discovery process that starts by identifying different communities' core needs, requirements and demands. Then it is a matter of aligning the housing, care and services with the specific group. This will count for (e.g.):

- food and dining options that support not only optimal nutrition but also changing tastes and cultural preferences
- resident activities, socialization, and lifelong learning, which include technology
- technology that maintains health, safety, and security, including predictive health physical plant, housekeeping, condition, lighting, and design/floor plan.

10.2. Conclusions

The living environment has a direct and indirect impact on health via exposure to environmental factors. A healthy living environment requires pleasant surroundings in which healthy choices are easy. A healthy living environment should encourage residents to be physically active and meet people as well as providing green space, water and little noise and air pollution.

Differentiation of housing, care and services comes with a cost, and therefore encounters a moral dilemma. Differentiation - and the level of it - in the care of the older population is a societal and political choice.

References:

Nicholson, R. (2018, April 2). How older adults' living environments affect quality of life

[Blog post]. Retrieved from: https://www.matherinstitute.com/2018/04/02/how-environmental-factors-impact-older-adults-quality-of-life/

11 PREJUDICE: NURSING HOMES HAVE NO PRIVACY AND LACK OF SELF-DETERMINATION

By Marcel Smeets

11.1. Overview

Moving into long-term care is often associated with loss of freedom and privacy. Freedom and privacy are often associated with a large number of private rooms, therefore choosing a specific care facility is made on the basis of the availability of a private room.

In addition, freedom and privacy are associated with the concept of "home", which can be associated with having a private room in long-term care. Private space, whether in a single-occupancy room or a room shared with other residents, impacts this sense of home. The desire for a private room may have a foundation in having opportunities to be alone, wishing for privacy, and being surrounded by personal belongings. Central to nesting and the creation of attachment to place is spending time in one's room or apartment and being engaged in domestic chores. This is stressed in the need for being alone and withdrawing to a private room with the opportunity personalise the environment. The need for privacy seems to be a main driver for having a private room. Private rooms govern the opportunity to talk with others in private or to withdraw from communal living areas.

Nevertheless, "privacy" and "private rooms" are not the same. One can feel privacy in a group accommodation or miss privacy in a private room, and 24/7 support is easier and better provided in group

accommodation than in separate units. The most important aspect is to provide an adequate quality of care.

11.2. Conclusions

Privacy in residential care settings is based on prejudice, and the concept is not to be confused with living in private rooms. The care process may require faster access for and supervision of older people living with certain, severe conditions. Care quality and feelings of privacy can be obtained if both are understood by care receivers and carer givers.

12 PREJUDICE: PEOPLE DEPENDENT ON CARE NEED HIGH EDUCATED PROFESSIONALS WHO TAKE CARE OF THEM

By Aad Koster

12.1. Overview

Perhaps it has always been a discussion, but certainly in the last decade the quality of care for the older population is a (social) media topic on a political level and in many other places. Almost immediately after each incident in the elder care new regulations are being requested, and often a plea is made for more highly educated staff. The idea is that with higher educated staff, the care quality will improve. In many countries, governments demand that a certain percentage of staff be educated to the highest level. The assumption is that the higher the level of education of the total, the higher the probability is of good quality of care.

This assumption, and the policy based on it, denies that quality exists in aspects beyond taking care of the physical conditions of the older population. In various research, it is well known that for much of the older population physical disabilities are not the biggest problem, but instead loneliness, boredom and lack of significance.

For instance, Machteld Huber published her research on Pillars of Positive Health in 2013 and was published in the British Medical Journal in 2016.

She operationalized "Health as the ability to adapt and to self-manage" to a set of 6 pillars:

1. Bodily functions;
2. Mental functions and perception;
3. Spiritual dimension;
4. Quality of life;
5. Social and societal participation;
6. Daily functioning.

To support the older population to strengthen their ability to adapt and to self-manage, not only highly educated nurses (for pillar 1) are needed, but other professionals with specific skills are needed. Moreover, it is necessary to involve volunteers, family and other people from the social network of the older population to contribute to giving attention to the other 5 pillars.

12.2. Conclusions

Attention is the main angle of approach our industry is working towards for the older population: how was their life, what were/are their most important moments, which relationships they had/have with family and friends, what are their hobbies, life philosophy, habits and wishes? How can we learn more and understand how we can best support the older population in strengthening their resilience? Chances are that, besides the pillar of the bodily functions, the other pillars are more important for the older population. It is even possible that by strengthening the other pillars the need for support of bodily functions could diminish.

To strengthen the other 5 pillars, care assistants, volunteers, family, friends and other members of the social network, sometimes technology and - last but certainly not least - the older person themselves can play a bigger role than highly educated nurses and doctors. That does not mean that we no longer need this skill set, but it means that government-regulation c.a. should not focus only on highly educated professionals.

12.3. Recommendations for EAN members

It is important that EAN members spend more time exploring who are they working for. More attention should be given to the way of living, habits, wishes and needs of clients and residents. Members should train their staff to do this. Additionally, they need to encourage partici-

pation of volunteers, family, friends and other people from the social network of residents or clients at home.

Regulators and governments must realize that it is essential to have a good mix of skills and grades, matched to the nursing and care needs of clients and residents, in order to achieve a better quality of care. They must promote the approach of personalised care. They can make the regulation for highly educated staff less obligatory and give more space and budget to care-organisations to take enough time to explore the characteristics of their residents and clients.

The interfaces used by banks, insurance companies and also the care organisations for older people are far too complicated. EAN members should review their own online client response, login procedures and digital infrastructure.

References:

Huber, M., Knottnerus, J., Green, L., et al. (2016) How should we define health?

BMJ. 1(343), doi:10.1136/bmj.d4163.

13 PREJUDICE: AGEING IS A DISEASE

By Freek Lapré

13.1. Overview

With this prejudice, older people are seen as people who are sick and who need to be intensively checked for (a progressive) disease. We call this medicalisation. Medicalisation is defined as "the process by which some aspects of human life come to be considered as medical problems, whereas before they were not considered pathological" (Maturo, 2012).

An editorial of The Lancet (2018) suggests that the door is open to treat ageing as a disease. The article refers to the WHO, which implemented an extension code for 'Ageing related' (XT9T) diseases, defined as those "caused by pathological processes, which persistently lead to the loss of organism's adaptation and progress in older ages". But actually, this editorial only focusses on the medical perspective. This could lead to positioning care for older people as a health care sector instead of a social sector.

Being frail is not the same as being sick. The question is how many old people are really sick? Longevity is influenced by educational level, financial status, social engagement, having a job (and one you enjoy), race, religious inclination, and attitudes to life. It is wise to be prudent about weight, diet, and alcohol; to take regular exercise; and to avoid smoking.

To measure how healthy older people are, the indicator "healthy life years" (HLY) is used. HLY is defined as the number of years that a person is expected to continue to live in a healthy condition. A healthy condition is defined as the absence of limitations in functioning/disability. This indicator is also called disability-free life expectancy.

This indicator uses a narrow definition of health, and in using it, ageing becomes unhealthy as you begin experiencing some limitations in walking, taking the stairs etc.

HLY's are self-reported to a certain extent and therefore can be considered as limited. The data are biased by the respondent's subjective perception and are also influenced by social and cultural background, which causes different interpretations of what it means and how it feels to be healthy.

Another limitation in regards to the way the data is collected is the exclusion of people who live in residential care facilities. These people are expected to be more likely to face limitations than the rest of the population living in private housing.

25% of genetics contribute to your lifespan (Mulley, 2012). If you live in a so-called 'Blue Zone', you have a higher chance of entering old age in good health; for example, in Okinawa, Japan; Nicoya, Costa Rica; Loma Linda, California; Icaria, Greece and Sardinia, Italy. As a result of a healthy lifestyle they are areas with the longest healthy life expectancy in the world.

People in Japan live on average 83 years while in Malawi the average is 43 years.

People in Europe have a life expectancy at birth of 83.7 years for women and 78.2 years for men (Eurostat, 2019).

In Europe the proportion of people 80 years and over will rise between 2018-2100 from 5.6% to 14.6%. This is a rise of 250%.

Dementia is seen as a big burden. The chance that you will develop dementia as you get older is as follows (figures 2018):

- overall 7% of the population in the EU-28 are living with dementia
- 1% of people aged 60-64 years are living with dementia

- 40% of people over 90 are living with dementia.

In 2015, both women and men at the age of 65 in the EU can expect to live 9.4 more healthy life years. The highest numbers of healthy life years at the age of 65 were recorded in Sweden (women: 16.8 years, men: 15.7 years), Malta (women: 14.0 years, men: 13.4 years) and Germany (women: 12.3 years, men: 11.4 years).

The use of residential care facilities varies within the EU. The average is about 5% of people of 65 years and over (EC, 2018), with variation between North Western Europe.

13.2. Conclusions

The conclusion is that ageing is not a disease. A more dominant medical approach is not necessary because older people are just living their life like others. Of course, we need to acknowledge that older adults can have diseases, and are more susceptible to some of those – including frailty. But natural decline in physical and cognitive ability as a result of aging should also not be seen as a disease. People who are aging become frail, meaning that they have to give more attention to their health and social relations. This can be supported physically by health care workers. Social prevention can be carried out by social workers. This means that prevention is a key component in caring for older people.

Most older people live at home, meaning that community programs can be a preventative instrument in care for older people.

This must be secured in government programmes in the context of an ageing society.

13.3. Recommendations for EAN members:

For recommendations we refer to the EAN report about the future of long-term care, which describes the need for de-medicalisation and how to de-medicalise care for older people in the future. You can download the report from: https://www.ean.care/media/fileman/LTC_2030_ebook_2nd_edition_v2.pdf

References:

Ebrahim, S. (2002). The medicalisation of old age. BMJ, 324(7342), 861–863.

Eurostat (2019) Life expectancy at birth, Retrieved from:

https://ec.europa.eu/eurostat/statisticsexplained/index.php/Mortality_and_life_expectancy_statistics#:~:text=Overall%2C%20between%202002%20(the%20first,and%203.9%20years%20for%20men.

Maturo, A. (2012). Medicalization: Current concept and future directions in a Bionic Society.

Mens Sana Monographs, 10(1), 122.

Mulley, G. (2012). Stop the medicalisation of old age. BMJ, 344(2), 802–803.

Editorial (2018), Opening the door to treating ageing as a disease, The Lancet, 6, 587

14 PREJUDICE: OLD PEOPLE CANNOT HANDLE TECHNOLOGY

By Freek Lapré

14.1. Overview

Old people are viewed as not being able to handle technology as the current older generation was raised during a time that information technology was not present in daily life. There has been a growth of technological information and communication applications, which must be made senior user friendly, or be designed to support functions that decline with age, such as reminders to take medication.

However, the question is, can older people not handle technology, or is it that technology is not user friendly for older people?

There is another kind of technology that is used by seniors: assistive technology (AT). AT is a form of technology that supports older people in maintaining or restoring independent living. Therefore, this form of AT is also called Ambient Assisted Living (AAL). AAL can be defined as "the use of information and communication technologies (ICT) in a person's daily living and working environment to enable them to stay active longer, remain socially connected and live independently into old age" (www.aal-europe.eu)

The development of technology for older people has traditionally focused on healthcare aspects by developing sensor technology in smart homes (Salah et al., 2015). Nowadays, there is more focus on interactive, communication and robotics technology.

Technology is also used to promote movement and physical activity for older people. For instance, in more and more care facilities it is possible to ride a bike trainer while seeing your home-village on a screen in front of you. It feels like you are cycling through your village and residents like it very much. This is a good example of a combination of technology with active ageing.

According to No Isolation (2018):

- Many seniors struggle with touch screens due to a condition called leathery

fingers

- Many seniors experience reduced mobility and a lower income, which makes it

more challenging to meet friends in person.

- Mastering new technology is often complicated as the seniors have no experience in using technology to use as a baseline. Seniors generally have a lesser frame of reference to enable them to absorb new knowledge.
- 83% of seniors between 64–74 years of age use the internet on a weekly basis or more frequent.
- in 2014 96% of seniors over the age of 67 own a mobile phone, but under half own a smartphone.

The consequences of the COVID-19 crisis and lockdown in residential care and at home, will probably give a boost to the use of ICT-applications by seniors (Kowalick, 2020).

14.2. Conclusions

The prejudice that older people cannot handle technology is false. The question is more if technological applications recognise the specific needs of older people to handle the applications, not the technology behind it. The technology market is more a push market, which is understandable in terms of innovation, but that is not enough. Tech developers must listen more carefully to the older consumers about how to handle their applications. A striking example is an app that designed for people living with dementia at home. By using augmented reality, people are able to find their medication in their own home. The older person living with dementia has to look through a mobile phone to see the directions projected in their own home, but the question is will

people with dementia look through their phone?

14.3. Recommendations for EAN members

EAN members should urge tech companies to involve seniors, care providers and occupational therapists during the design and test phase of technological applications.

Secondly, EAN members should stimulate their governments make this involvement mandatory before a product is allowed on the market. A label that an application is senior friendly issued by EAN of consumer organisations is another possibility.

Thirdly, EAN members should enthuse their staff members about the advantages and possibilities of technology. In many cases there is still a lot of resistance to use more technology.

Fourthly, EAN is working on a programme to promote ICT technology for older people through education and training.

References:

Kowalick, C., (2020), Survey: Seniors embracing technology amid COVID-19 pandemic

Retrieved from: https://eu.timesrecord-news.com/story/news/local/2020/04/10/covid-19-moves-seniors-embrace-technology-coronavirus-survey/5122728002/

No Isolation. (2018). Why do many seniors have trouble using technology? Retrieved from:

https://www.noisolation.com/global/research/why-do-many-seniors-have-trouble-using-technology/

Salah, A., Kröse, B., & Cook, D. (2015). Behavior Analysis for the Elderly. In: Human

Behavior Understanding. Proceedings 6th International Workshop, HBU 2015 Osaka, Japan, September 8, 2015 (pp. 1-10). Cham, Switzerland, Springer International.

15 PREJUDICE: OLD PEOPLE ARE NOT ACTIVE ANYMORE AND CANNOT HAVE FUN

By Freek Lapré

15.1. Overview

With this prejudice old people are sometimes viewed as grumpy, complaining people who have no fun in life anymore and only sit at home watching television or staring out of the window.

The first question is what does it mean to be active? Browsing the term "active seniors" on the internet shows that all websites refer to "active" in the sense of "working".

Active can also mean physically active, in the sense of sports, for example. The term for this is "active ageing", which is promoted by the WHO as well as many governments and organisations (WHO, 2020).

Fun is a broad concept. In this context it can be translated as leisure activities that seniors enjoy, including travel.

Social interaction is especially important because it prevents feelings of isolation.

Some facts
In 2016, 9.5% of the population aged 65 to 74 were economically active (employed or unemployed) in the EU, compared with 77.5% of the population aged 20 to 64 (European Commission, 2020).

Studies show that about two thirds of adults aged 55–69 years and about three quarters of those over 70 seldom or never participate in

sport or exercise (WHO Europe, 2020).

Tourists aged 65 or over accounted for nearly 1 in 4 tourism nights for private purposes by EU residents in 2018, while people aged 55+ accounted for 41%.

Tourists aged 65 or over accounted for nearly 1 in 4 tourism nights for private purposes spent by EU residents (European Commission, 2020).

In many countries, it is recognised that you must distinguish between people in the third phase of life (between 60 and 80 years) and in the fourth phase of life. More and more people in their third phase of life are very active, playing in sport clubs, volunteering, taking care of grandchildren, or taking part in cultural hobbies or community-building. This is due to the fact that new older generation tends to be more energetic and also more assertive in what they want to do in life.

Even in their fourth phase of life, some people contribute a lot to their local community and are committed to idealistic goals, like the system of Ibasho in Japan.

Older people are still interested in a lot of actual issues. In the Netherlands there is an organisation of young students, visiting nursing homes and care-facilities to give presentations of aspects of their studies. It is a nice way to keep brains active.

15.2. Conclusions

Older people may not be economically active, but in a broader sense in terms of going out an, travelling and leisure, they are very active. More encouragement to take part in sport or other physical activity might be necessary to maintain physical health. This means that overall, this prejudice is largely false.

Promoting participation in cultural activities shows that older people can still dance, sing or perform. This leads to healthier ageing, feeling more positively in general and stronger resilience.

15.3. Recommendations for EAN members

EAN members should promote more sports and cultural activities in cooperation with cultural and sport-associations and organisations from local neighbourhoods or cities. For home care clients guidance should be provided on how to promote activity, such as informing clients on where they can go for sport, cultural activities etc.

References:

European Commission (2018), Challenges in long term care in Europe, A study of National Policies, Brussels.

WHO (2020), Active ageing: physical activity promotion in elderly. Retrieved from:https://www.euro.who.int/en/health-topics/disease-prevention/physical-activity/activities/hepa-europe/hepa-europe-projects-and-working-groups/active-ageing-physical-activity-promotion-in-elderly.

16 PREJUDICE: ELDER ABUSE

By Markus Mattersberger

16.1. Overview

Mistreatment of older people occurs in various forms. In addition to physical and psychological abuse, other forms of abuse include neglect, sexual violence, financial exploitation, and restrictions on free will. According to the WHO report 2011, at least four million older people in the WHO European Region experience forms of this abuse each year (WHO Europe, 2011, p. VIII). As the number of older people increases, it must be assumed that the number of cases of abuse will also increase.

Currently, 15.4% of older people living at home experience abuse and 33% of older people living in an institutional care setting (Yon, Lam, Panssmore , Huber, Sethi, 2020):

Although there are isolated efforts by European countries to reduce this abuse, the issue is not discussed enough.

According to surveys, assaults occur mainly in the home setting, but also in inpatient facilities, and the caregiver is often considered to be overburdened by excessive demands (Sowarka, Schwichtenberg-Hilmert, Thürkow, 2002, p. 51). Studies show that older people living with dementia and/or with a disability that leads to increased dependence on caregivers increases the risk of elder abuse. Similarly, living in the same household as the offender increases the risk. The perpetrators are usually partners, descendants or other relatives, although equally, professional care givers and visitors can also be

perpetrators in institutional as well as domestic settings (WHO Europe, 2011, p. XI). According to Osterbrink and Andratsch, the act of violence is preceded by events that have led to frustration or disappointment on the part of the carer or the person in need of care, and fear can also be a trigger (Osterbrink & Andratsch, 2015, p. 158). „Once a spiral of violence has developed, it is often no longer possible to determine who is actually the victim and who the perpetrator and whose behaviour was the beginning." (Seidl quoted in Osterbrink/Andratsch, 2015, p. 158)

„Shame, grief, dependence on help and care and mental deterioration are considered to be the reasons that the number of undetected cases of abuse in old age is high. Reliable estimates suggest that for every reported and confirmed case of abuse and neglect, there are five more cases that go undetected." (Sowarka, Schwichtenberg-Hilmert, Thürkow, 2002, p 49)

In addition, the issue of structural violence is relevant primarily in the stationary setting. According to Staudhammer, it is seen and indicated by most employees as the main risk factor for violence in health care professions. Structural violence is to be understood in particular as the house and home rules, the personnel equipment, close daily structures in addition, the spatial equipment and the associated lack of privacy and intimate sphere (Staudhammer, 2018, p. 11). Structural violence can only be influenced by those responsible for the institutions to a limited extent, because they too are forced to make do with the structures that society provides them with to cope with their tasks. In this context, those cases of violence and abuse that occur between residents in care facilities but also towards care personnel, which, in addition to the causes already mentioned, also occur due to inadequate spatial solutions, must also be mentioned. Zeh et al. state: „Uncomfortable and overcrowded rooms as well as lack of privacy lead to conflictual behaviour. (Zeh quoted in Wörndl, 2018, p. 63).

16.2. Conclusions

The assessment that a large amount of abuse and neglect remains undetected illustrates the scope of the issue and at the same time the extent of the taboo. On one hand, the assumption that every individual in a society could also become a perpetrator if the relevant influencing factors were to interact with each other may contribute to the taboo, as does society as a whole bearing responsibility. This can be explained relatively easily by questioning what resources and structures we are prepared to provide for the care of our older population.

There are already numerous national efforts to address the issue, such as emergency telephone lines, crisis counselling and telephone lines to register complaints, ombudsman services, legal regulations and contact points (Sowarka, Schwichtenberg-Hilmert, Thürkow, 2002, p. 51). The situation must be consistently followed up and addressed, but at the same time it we must avoid attacking actors collectively - in many cases they themselves are not only perpetrators but also victims of the situation. Condemnation reinforces the taboo and prevents an open culture of error.

Efforts need to be stepped up and awareness raised, so data collection and research projects should be sought.

16.3. Recommendations for EAN members

„Violence always results from the interaction of various complex causes. Moreover, the causes influence each other; this makes it even more difficult to control them. (Osterbrink/Andratsch, 2015, p. 157) In particular, it is important to identify the causes of violence, to consider them together and to fight them. Above all, instances of overburden for family carers and professional service providers must be defused. This can be achieved, among other things, by ensuring sufficient staff presence, well-trained employees, good working conditions, fair pay and appreciation for the work. These aspects are to be supplemented by professional support in the domestic sphere and by appropriate quality assurance and control.

In general, early detection of violence is essential both in facilities and in the home. In institutions, this primarily involves the manager's influence on employees who, due to their personal circumstances, could be more susceptible to violent behaviour. In the home setting, for example, social workers have an essential role to play in recognizing that partners and/or families are already exhibiting some violent behaviour prior to overwork situations

Nursing staff in the home setting as well as in the inpatient sector should be offered relief both physically and psychologically.

EAN members can create an appropriate awareness of the interaction between cause and effect among those with political responsibility; but also for executives as it is important to create a corresponding awareness of the possibilities that lie within their sphere of influence. The „European Charter on Rights and Freedoms of Older People in Homes", which was signed by the then members of the association in 1994, can serve as a valuable basis for this.

It is also necessary to build up activities and measures to prevent mistreatment of older people on a solid data basis. „The lack of high--quality evaluation studies on interventions specifically designed to reduce or prevent elder abuse significantly limits the conclusions on which interventions could be most effective". (WHO Europe, 2011, p. XII) If this is of concern to policy makers, appropriate research should be supported and measures derived and implemented from the research findings.

References:

Oosterbrink, J., & Andratsch, F.(2015): Gewalt in der Pflege, Münche, Deutschland, C.H. Beck.

Sowarka, D., Schwichtenberg-Hilmert, B., & Thürkow, K. (2002), Gewalt gegen ältere

Menschen: Ergebnisse aus Literaturrecherchen. (DZA Diskussionspapiere, 36). Berlin: Deutsches Zentrum für Altersfragen. Retrieved from: https://nbnresolving.org/urn:nbn:de:0168-ssoar-370061

Staudhammer., M., (2018), Prävention von Gewalt und Machtmissbrauch in der Pflege, Berlin, Springer

WHO Europe (2011): European report on preventing elder maltreatment, Retrieved from: https://www.euro.who.int/__data/assets/pdf_file/0010/144676/e95110.pdf

Yon, Y., Lam, J., Passmore, J., Huber, M., Sethi, D. (2020) The Public Health Approach to

Elder Abuse Prevention in Europe: Progress and Challenges. In: Phelan A. (eds) Advances in Elder Abuse Research. International Perspectives on Aging, vol. 24. Springer, Cham. https://doi.org/10.1007/978-3-030-25093-5_15

Wörndl. A., (n.d.): Territorien, Konflikte und Raum – Räumliche

Konfliktprävention in der stationären Altenhilfe – Gestaltungsprinzipien für soziale Handlungsräume [Blog post]. Retrieved from: https://www.fokus-sozialmanagement.de/raeumliche-konfliktpraevention-in-der-stationaeren-altenhilfe-gestaltungsprinzipien-fuer-soziale-handlungsraeume/.

17 PREJUDICE: DEATH IS OUR ARCH ENEMY

By Megan Davies & Markus Leser

17.1. Overview

Dying and death (end of life) have no place in today's society. Those who die lose (life) and neither medicine nor an achievement-focused society can be seen to lose. Since no one likes to talk about losing, the end of life in its entirety becomes a taboo subject and is treated as being non-existent.

Death at any age is not openly talked about in most cultures. To discuss death openly is to admit that it happens and then we have to face it. However, death is not unique to a certain age of person, it is the only certainty of life and affects everyone, regardless of age. To talk about it is not to make it happen, it is to accept it, and this should be encouraged.

In some cultures, this is already the case. There are cultures that believe that to die is to enter paradise, which is something that should be celebrated. It provides relief to suffering and a passage to another life. It is just another event within a life - the final event on earth.

In some countries, assisted death is becoming more common as an option in specific cases, particularly in older age, regardless of whether a physical disease is present. The terms existing around this are currently 'assisted suicide', and in some countries 'assisted murders'. These terms hold such an event in a negative and even criminal light, rather than understanding how this can be a positive for the person who has chosen this option. It is not done in despair or hastily,

it is a considered decision made with experts in a way that educates the person and their family, helps them understand their journey and respects their choice at the end of life.

Death is a part of life and should be considered and respected as such. Death is painful and upsetting for the people left behind, but this should not prevent an open dialogue from occurring to help with acceptance, for both the person dying and the people saying goodbye.

17.2. Conclusions

Discussions about death should not be seen as morbid, but should be an open dialogue to increase understanding and acceptance. This acceptance can allow people to grieve properly, therefore improving mental health.

Not acknowledging death as a part of life does not make the outcome easier to process, nor will it prevent it.

17.3. Recommendations for EAN members

A link-up with the „Palliative Care" project can be established here. The aim here is to show how the „good life" can continue to the very end (through good practice examples).

We need to open up a dialogue about death and dying to encourage discussion about this as a part of life.

It would be helpful if good practice examples from all over Europe on how to deal with dying and death in long-term residential care could be collated via the EAN.

18 PREJUDICE: LOVE AMONG OLDER PEOPLE

By Freek Lapré

18.1. Overview

Love among older people itself is not seen as a taboo in society. A search of literature produced over the last 5 years shows no articles or research particularly focussing on love among older people in society. The taboo arises when the context of a "normal" age is changed into a residential care setting. Additionally, very little research exists evidencing love between residents living with dementia in a residential care setting.

The taboos deal with:

1. Loving relationships between residents with or without a spouse at home
2. Being LGBTQ+ is sometimes a taboo among residents and staff. The current older generation has largely been raised with the assumption that heterosexuality is the norm (also driven by religion). Therefore, different views on sexuality can be seen as unacceptable by other older people, and sometimes also by the care staff
3. Being in or entering into a LGBTQ+ relationship as a resident can be considered a taboo, which is very difficult to discuss with other residents or staff.

1. A new, loving relationship between residents who have no spouse is larhely accepted, but occasionally family struggle with it. The reason for this can be that the memory of a deceased spouse leads to painful feelings

among family members, especially children. Another reason is that family think that it is not how it should be.

A more painful situation occurs when there is still a spouse at home. Then the loving relationship is seen as adultery.

The question arises of why these situations are treated differently for older people in a residential care context, when actually this is just a normal part of life.

Is vulnerability a factor that influences the attitude towards love in a residential care setting? When people living with dementia are involved and the relationship has a positive influence on their wellbeing, must such a relationship be forbidden?

2+3. Research shows that LGBTQ+ residents suffer from social exclusion, not feeling safe and an increasing desire to be yourself (Leyerzapf et al. 2016).

The difficulty of non-acceptance of LGBTQ+ residents in residential care facilities has led to the opening of facilities that are focussing on LGBTQ+ residents.

In 2014 the first LGBTQ+ care home was opened (Otis, 2016). Other facilities can be found in the Netherlands and Switzerland. Here LGBTQ+ residents can live the life they wish without being concerned about other residents.

18.2. Conclusions

The conclusion is that this subject is still a big taboo among residents, family, staff and management and needs attention from care providers.

18.3. Recommendations for EAN members

Management of facilities should, when loving relationships occur, assess the attitude of the family. Together with a social worker they should discuss how to deal with the relationship. The wellbeing of the resident must be the main focus. In

the situation that the resident is living with dementia, it is easy to say that they do not realise what they are doing, but is that really the situation?

Specific LGBTQ+ care homes do not solve the problem, but cause further segregation. Integration and acceptance of LGBTQ+ in society needs to be promoted in care for older people.

This is not easy since residential care facilities are close communities, but the population in care facilities reflect society. Therefore, to make a facility more LGBTQ+ friendly, social norms need to be addressed (Leyerzapf et a., 2016) in a way that also opposite values and attitudes can be will be present. This is something management teams in facilities must initiate among residents and staff.

National associations should start training programmes, workshops, conferences about this topic and possible solutions to open the discussion.

Special attention is needed for relationships and sex between people living with dementia.

References:

Leyerzapf, H., Visse, M., De Beer, A., & Abma, T. (2016). Gay-friendly elderly care: creating space for sexual diversity in residential care by challenging the hetero norm. Ageing and Society, 38(02), 352–377.

Otis M., (2016) European LGBT Elders. In: Harley D., Teaster P. (eds) Handbook of

LGBT Elders. Springer, Cham.

19 PREJUDICE: SEXUALITY IN OLD AGE

By Freek Lapré & António Gouveia

19.1. Overview

Sexual function and activity in old age have been inadequately studied (Kalra, Subramanyam, & Pinto, 2011). At any age, sexuality is an important component of emotional and physical intimacy that people experience throughout their lives (Camacho & Reyes-Ortiz, 2005; Gewirtz-Meydan, et al., 2018).

The commonly held assumption that old age begins after 60 must be challenged; in fact, many changes experienced by older people begin earlier in life (Kalra, Subramanyam, & Pinto, 2011).

Different studies reveal diverse results regarding the presence of sexual desire, activity, and function. Some show some a decline by the age of 60, which is more prominent in women, but associated with chronic illness (Kalra, Subramanyam, & Pinto, 2011); others reveal that a significant percentage of older people have sexual intercourse (with masculine advantage), but associated with sexual dysfunctions that, for the most part, are left unaddressed (Nicolosi, Buvat, Glasser, Hartmann, & Laumann, 2006). It is important to discard disease or side effects of medication and even harmful lifestyles when faced with sexual dysfunctions in ageing (Camacho & Reyes-Ortiz, 2005) before jumping to the conclusion of a lack of libido.

Nevertheless, sexual interest remains more present than activity, even in very advanced age (Buono, et al., 1998).

Other variables that have impact both in sexual interest and activity, are as follows: being male, married, younger and cognitively unimpaired, having a higher educational level, being self-sufficient and satisfied with the present life, and social functioning (Buono, et al., 1998).

False expectations for older people stem from ideals of beauty, centralization of the biomedical perspective on sexuality of older adults, and the association of sex with reproduction (Gewirtz- Meydan, et al., 2018).

When sexuality in old age is discussed, some people feel a sense of discomfort. Sexuality in old age is something that is difficult to talk about. Love is much easier to discuss because it is such a broad concept that contains also sexuality without directly mentioning it.

The taboo around sexuality begins in puberty – new feelings around sexuality are difficult to discuss, and we do not want to imagine our parents sex life.

That is what our imagination tells us, but sexuality is more than "doing it..."

The World Health Organization (WHO) says the following:
Sexual health cannot be defined, understood or made operational without a broad consideration of sexuality, which underlies important behaviours and outcomes related to sexual health. Therefore, the working definition of sexuality is:
"...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."

The WHO definition clearly relates sexuality to health. This means that poor health affects sexuality negatively and vice versa. This is not surprising since the foundation layer of Maslow's needs pyramid are physiological needs, including sex.

Sexuality and older people

A recent systematic review of 20 studies about sexuality in old age (Gewirtz-Meydan et al. 2018) gave the following results:

- Social legitimacy of sexuality in later life:
  - older people think that other people presume that they are 'sexually invisible' (p. 4)
  - women find it uncomfortable to discuss the "social silence regarding their sexuality and intimacy" with friends
  - the taboo of sexual visibility of older people is related to the (Western) orientation to youthfulness and beauty

- health affects sexuality: this confirms what was previously stated that there is a relation between sexuality and health:
  - older people feel that the ageing process affects their sexuality
  - physical limitations or illnesses limit the ability to be sexually active (p. 8)
- narrow definition of sexuality:
  - sexuality is narrowly defined as having intercourse/penetrative sex
  - it is a norm that relationships must include intercourse.

Sexual rights

There is a growing consensus that sexual health cannot be achieved and maintained without respect for, and protection of, certain human rights. The working definition of sexual rights given below is a contribution to the continuing dialogue on human rights related to sexual health.

"The fulfilment of sexual health is tied to the extent to which human rights are respected, protected and fulfilled. Sexual rights embrace certain human rights that are already recognized in international and regional human rights documents and other consensus documents and in national laws" (United Nations ...).

Rights critical to the realization of sexual health include:

- The rights to equality and non-discrimination
- The right to be free from torture or cruel, inhumane or degrading treatment or punishment
- The right to privacy
- The right to the highest attainable standard of health (including sexual health) and social security
- The right to marry and start a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage
- The right to decide the number and spacing of one's children
- The right to have information, as well as education
- The right to have freedom of opinion and expression, and
- The right to an effective remedy for violations of fundamental rights.

Sexual needs

The literature published in recent years on sexual satisfaction and body image in older adults reveal an interesting pattern in older women, who appear to be less vulnerable to body-related dissatisfaction in sexual contexts than younger women. Findings from different countries show that substantial proportions of older people are satisfied with their sex life, and these results may be increasing across cohorts (Træn, et al., 2017). Diseases (e.g. cancer) and physical functions (e.g. urinary incontinence) that impair body images should be addressed simultaneously from a medical and a psychological perspective. Training in the use of compensatory strategies to minimize the impact of physiological changes in sexual response (Zeiss & Kasl-Godley, 2001) and the development of a positive psychological mindset towards these strategies is required. The reductionist view of sexuality merely as sexual intercourse excludes some older people from sexual activity because intercourse is often affected by physiological changes in bodily functions. For some older people, representations of sexuality include terms of deep relational conditions between sexual partners – love, affection, respect, companionship, understanding – along with sex (Queiroz, Lourenço, Coelho, Barbosa, & Bezerra, 2015).

For older people residing in long-term care (LTC) settings the situation is even harder, because in most of these settings, resident's attempts at sexual expression are regarded as a problematic behaviour (Rheaume & Mitty, 2008). Although there is a recognition among the LTC staff for sexuality needs of older people, these are not regularly assessed due to staff discomfort about the topic, negative staff attitudes towards older people, as well as a lack of privacy and unclear institutional policy regarding the issue (Gewirtz-Meydan, et al., 2018).

Assisted living staff need information and tools to adequately address residents' sexual experience (Rheaume & Mitty, 2008). Also, aspects like residents' ratio's and dimensions (thus construction and equipment costs) of LTC facilities are relevant for the opportunity to address this issue.

Older people are challenged by ageist attitudes and perceptions that hinder their sexual expression. They are stereotyped as non-sexual beings who should not, cannot, and do not want to have sexual relationships. Expressing sexuality or engaging in sexual activity in later life is considered by many in society as immoral or perverted (Gewirtz-Meydan, et al., 2018). Specific, narrow societal norms and expectations were found to be main barriers to expressing sexual needs and sexuality, and to discussing sexually related issues with professionals. Internalising societal norms and ageism caused sexual problems that were attributed to ageing to be viewed as normal and irreversible or untreatable (Gewirtz-Meydan, et al., 2018), thus strongly diminishing the quality of life of older people.

An adapted and fulfilled sexuality among older people is associated with several positive outcomes, namely wellbeing and specifically enjoyment of life (Smith, et al., 2019).

Further developments regarding the sexuality of older people imply the need for adoption of a biopsychosocial model as a multidisciplinary approach to sexuality in older stages of life. One that considers psychological and social factors such as stereotypes, gender socialisation, partner availability, socioeconomic status, ethnicity, religious

beliefs, and sexual orientation, in addition to biological influences (Gewirtz-Meydan, et al., 2018).

19.2. Recommendations for EAN members

What does this mean for providers of care for older people in general and EAN members in particular?

All care for older people must respect and comply with these human rights.

Within the context of the human rights what sexual rights can be defined for residents who receive care in a facility?

These sexual rights should be secured in the facility and if needed at home, but can be influenced by the social and cultural context. This means that there cannot be a uniform elaboration and application of these rights in a facility or when needed at home.
But minimum standards can be defined. If a facility wants to apply and secure sexual rights above minimum standards, it will encourage other providers.

Minimum standards for sexual rights are based on a conceptual framework for sexual needs management (Syme, Lichtenberg & Moye, 2016) that consist from the following eight categories and made operational by EAN:

- Address the issue: residents, staff and management recognise the sexual needs of residents and that these needs must be met according to the wishes of the individual resident
- Make environmental changes: facilitate intimacy and sexual activities between residents and their loves ones by a first knock policy, wider beds or putting beds together or to provide private space for lovers to spend intimate time together
- Identify staff expertise: an expert should be identified and present, who staff can turn to when seeking assistance when confronted with sexual needs of a resident. This is not necessarily a psychologist but can be a social worker or other staff member who is trained and experienced in these matters
- Provide education and training: This coincides with challenges around negative attitudes of

family, staff and management. Don't forget that residents don't live at your work, but you work in their home - you are essentially a guest.

- Educate about the sexual needs of residents and increase knowledge about sexual expression and consent. Education and training must also aim to increase staff awareness of their own attitudes. For example, staff should be educated about how to manage situations where clients have problems or cause problems because they suffer from the lack of intimacy and sexuality. Be aware what medication can diminish sexual desires and possibilities, but it can also lead to uninhibited sexual behaviour
- Assess sexuality initially: sexual assessment must be part of the intake and recurrently addressed to monitor the sexual needs and behaviours of residents
- Establish policies/procedures for sexual expression management. Although there is a recommendation to set formal policies and procedures, the question arises about whether this is needed. Some research directors felt comfortable by informal procedures. Policies can be formalised to secure the right to be free in sexual preferences like:
  - Being lesbian, gay, bisexual and/or transgender is equally accepted as being heterosexual
  - Zero tolerance on bullying because of sexual preferences among residents or between residents and staff
  - Accept open affection between residents independent from their sexual preference
- Develop assessment tools for sexual expression and consent, especially for residents living with dementia or cognitive decline. It is useful to have proper assessment tools in place
- Clarify legal issues: specific laws for sexual needs of people are mostly general or covered by general human rights laws. Therefore, a risk of lawsuits by those who opposes the sexual needs of residents, like family, is present. But in facilities, the needs of residents must come first and family second. A recommendation can be "the use of ombudsmen for patient advocacy and additional 'backup' to strengthen the evidence of their

(..staff..) decision to allow or not allow the intimate activity" (p. 7).

References:

Buono, M. D., Zaghi, P. C., Scocco, P., Urciuoli, O., Pauro, P., & De Leo, D. (1998). Sexual feelings and sexual life in an italian sample of 335 elderly 65 to 106-year-olds. Archives of Gerontology and Geriatrics, 26, 155-162.

Camacho, M. E., & Reyes-Ortiz, C. A. (2005). Sexual dysfunction in the elderly: age or disease? International Journal of Impotence Research, 17(1), S52-S56.

Gewirtz-Meydan, A., Hafford-Letchfield, T., Benyamini, Y., Phelan, A., Jackson, J., & Ayalon, L.(2018). Ageism and Sexuality. Em L. Ayalon, C. Tesch-Römer, & (eds), Contemporary Perspectives on Ageism (pp. 149-162). Cham: Springer.

Gewirtz-Meydan, Ateret; Hafford-Letchfield, Trish; Ayalon, Liat; Benyamini, Yael; Biermann,

Violetta; Coffey, Alice; Jackson, Jeanne; Phelan, Amanda; Voß, Peggy; Geiger Zeman, Marija; Zeman, Zdenko (2018). How do older people discuss their own sexuality? A systematic review of qualitative research studies. Culture, Health & Sexuality, 1–16.

Kalra, G., Subramanyam, A., & Pinto, C. (2011). Sexuality: Desire, activity and intimacy in the elderly. Indian Journal of Psychiatry, 53(4), 300.

Nicolosi, A., Buvat, J., Glasser, D. B., Hartmann, U., & Laumann, E. O. (2006). Sexual behavior, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World Journal of Urology, 24(4), 423-428.

Queiroz, M. A., Lourenço, R. M., Coelho, M. M., Barbosa, R. G., & Bezerra, S. T. (2015).

Social Representations of Sexuality for the Elderly. Revista Brasileira de Enfermagem, 68(4), 577-581.

Rheaume, C., & Mitty, E. (2008). Sexuality and intimacy in older adults. Geriatric Nursing, 29(5), 342-349.

Smith, L., Yang, L., Veronese, N., Soysal, P., Stubbs, B., & Jackson, S. E. (2019). Sexual Activity is Associated with Greater Enjoyment of Life in Older Adults. Sexual Medicine, 11-18.

Syme, M. L., Lichtenberg, P., & Moye, J. (2016). Recommendations for sexual expression management in long-term care: a qualitative needs assessment. Journal of Advanced Nursing, 72(10), 2457–2467

Træn, B., Carvalheira, A., Kvalem, I. L., Štulhofer, A., Janssen, E., Graham, C. A., . . . Enzlin, P.(2017). Sexuality in Older Adults (65+) - An Overview of the Recent Literature, Part 2:Body Image and Sexual Satisfaction. International Journal of Sexual Health, 29(1), 11-21.

Zeiss, A., & Kasl-Godley, J. (2001). Sexuality in older adults' relationships. Generations, 25(2), 18-25.

20 FUTURE ACTIONS AND POINTERS

As previously stated, this report was developed to open discussions about prejudices and taboos in society as a whole and particularly those surrounding the care of older people in residential facilities or at home.

As authors of this report, we believe that these discussions should start with the stakeholders in your care organisation. The best way to do this is most likely to pick a few of the prejudices and taboos mentioned in this report. Perhaps this discussion could be held in the first instance in separate groups of clients/residents, staff/professionals, volunteers, families of clients and residents. In some countries, there are also boards of clients, councils of professionals and supervisory boards. They can also be involved in these discussions.

In the next phase the discussion can be held in groups made up of all internal stakeholders. Try to find and present good practices and examples.

If this way of discussing with your internal stakeholders is successful, you could repeat it several times and pick up other prejudices and taboos mentioned in this report.
The outcome of these discussions could be shared with your national associations. It can also be interesting to publish the outcomes of discussions and conclusions drawn in order to communicate with all people and groups involved with your care organisation. In addition, these publications can also be used to open discussions with external stakeholders, such as senior organisations, politicians, policymakers, journalists and insurance companies.

And of course, we, as writers and representatives of EAN, are also very interested in your experience with discussions about this report. We would really like it when you send your experience to EAN.

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TABOOS AND PREJUDICES IN LONG-TERM CARE

(C) 2021, European Ageing Network

ISBN: 978-80-88361-16-9
ISBN: 978-80-88361-17-6 (online)

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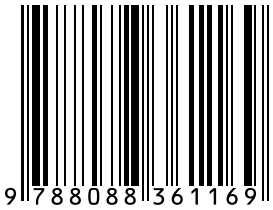

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