Summary report workshops

Knowledge sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

1. Background

Joint Programming Initiative 'More Years, Better Lives' (JPI MYBL) aims to complement, and provide a concrete perspective, to existing research on the issues regarding Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care" by involving policy makers, stakeholders, and researchers. The underlying document for the process is the red line document. The document provided a short background and summary of the state of the art on the topics of isolation and loneliness during the pandemic. During the knowledge sharing process this document would be expanded towards a state of the art document. The process consists of 4 workshops. All workshops will be attended by the whole group of stakeholders, researchers, and policy representatives

This report combines the summary reports of the three workshops. The first workshop was dedicated to stakeholders. The second to researchers, and the third to policy.

2. Workshop 1: stakeholder

AGE Platform and BAGSO's – Heidrun Mollenkopf

Priorities

In her presentation Heidrun stated that two elements of the redline document were a priority: The general attitude towards ageing. E.g 1) the call for older persons +65 to stay home and the paternalistic attitude (you're suffering, and we have to protect you...) and the fact that many decisions were made without asking what older people wanted. Here it is important to find out

- o By whom is it being exerted? Gov, family members, municipalities?
- o What is the impact on? Heterogeneity?
- o Impact different across European countries? If yes, why? Why there are different outcomes? The impact factors, the reasons behind

2) Ageism: we needed to know what kind of ageism? which one has the worst impact?

Overall we need to

- Agree on how older people will be actively included in the discussions
- know how feeling of loneliness and problems in care giving were developed at what speed in the past years? Did resilience last also during the 3rd or 4rth waves? Or did loneliness decrease because older people adapted to digital devices (or their home care or care givers

Policy use

Heidrun concluded that there was a lot of knowledge out there, but people needed to be made aware that it existed, it needed to be translated in a way that it can be used by policy.

After the presentation the group had time for a brief discussion. The overall conclusion was that they agreed that Ageism and especially the question: What type of ageism are we talking about? Was an important one. Also the element of fear was acknowledged. Regarding the good practices the statement was made that good practice did not always mean that they were effective. More knowledge was needed.

Good practices:

Heidrun gave examples of several good practices. She stated that several of BAGSO's press releases, statements, etc. were taken on board by Ministries but still there was not enough knowledge about how they were used or implemented

EUPrevent PROFILE - Elke Tipplemann

Elke presented the cross broader project euPrevent PROFILE (*prevention of loneliness of older people in the Euregio*). The project would stimulate cross-border cooperation with the aim to prevent and combat loneliness in older people, to promote knowledge exchange, best practices and implementations, to increase awareness of the effects of loneliness and to connect people, experts and organizations who have already been active in this field.

As priorities she identified the need to develop guidelines about effective interventions and effective practices and Lack of successful approaches in crisis management targeting vulnerable groups. Inside the programmes related to the project family carers were included. There was a need for policy recommendation regarding informal care e.g the need for emergency care which could be provided by emergency teams. In some cases, informal care practices do not exist.

She stated that research should focus on

- Higher risk population with multiple forms of vulnerabilities

- identifying the success factors

- the intergenerational approach. It may help to get a better picture of what happened in times of crisis

Policy use

The development of new policy was one of the aims of the PROFILE project. JPI MYBL's work combining the demographic problems with the impact of COVID, loneliness and older people could have an added value to the PROFILE project

Good practices

Several examples of good practices were given. One in the German Malteser region were the Ministry for Family, Youth and Senior stimulated the expansion of voluntary visiting services such as

- o new services like telephone visits

- o New forms of shopping together or visiting Cultural events

- o Recruitment new volunteers

About the recruitment of new volunteers: the associated partners in the project are stakeholders in the communities and one of the questions they had was how can you avoid volunteers disappearing in times of crisis? One of the solutions was the recruitment of younger people which resulted in mixed groups.

SHIFT and COFACE - Annemie Drieskens

Annemie Drieskens from COFACE families Europe presented SHIFT: Shedding light on the S.H.I.F.T. towards meaningful inclusion in Europe. They are tools to develop the inclusive community based care
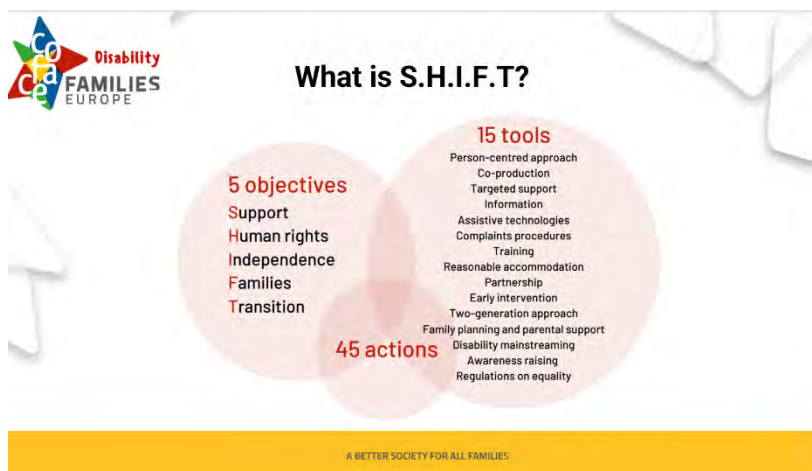
infrastructures of tomorrow. Although the example was focused on the persons with disabilities their families the procedure could also be implemented to achieve the same for older persons in relation to loneliness and Covid -19.

The group concluded that this was a good example and building a such a tool to tackle loneliness in older persons would be interesting.

For the older population besides the family the inclusion of friends and non-related partners in the combat of loneliness is essential

2.1.Conclusion workshop 1

The red line document is a good starting point for discussion. It gives clear direction on important issues but is not an exhaustive literature as many papers are still coming out. The stakeholders emphasise in their presentations that

- older people themselves must be included in the discussions
- there are good practices and tools out there. They influence 'local' policy but its difficult to measure their impact.

Annex I - List of participants

Annemie	Drieskens	Coface Families Europe	Belgium
Christina	Victor	Brunel University London	United Kingdom
Clemens	Tesch-Roemer	German Centre of Gerontology (DZA)	Germany
Elke	Tippelmann	BAGSO e.V.	Germany
Elsa	Perdrix	Dauphine University	France
Giovanni	Lamura	INRCA IRCCS - National Institute of Health and Science on Ageing	Italy
Heidrun	Mollenkopf	AGE Platform Europe	Belgium
Jennifer	Bethell	KITE Research Institute, Toronto Rehabilitation Institute – University Health Network	Canada
Oliver	Huxhold	German Centre of Gerontology (DZA)	Germany
Theo	Van Tilburg	Vrije Universiteit Amsterdam	Netherlands
Tineke	Fokkema	Netherlands Interdisciplinary Demographic Institute (NIDI)	Netherlands

Organisation:

Bruno	Arpino	Coordinator JPI MYBL knowledge sharing Process
Giuseppe	Gabrielli	JPI MYBL General Assembly member
Denice	Moi Thuk Shung	MYBL secretariat
Nathalie	Noupadja	Moderator & Chair JPI MYBL societal advisory board

Annex II – Programme workshop 1

A knowledge sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Date and time: 21 December 2021 from 13.30 till 15.30 CET

Meeting via zoom

Organization: Bruno Arpino, Nathalie Noupadja, Giuseppe Gabrielli

Support and documentation: Denice Moi Thuk Shung and Lianne van Horen, MYBL secretariat

Participants: stakeholders, researchers, and policy representatives

Objectives of the knowledge sharing process:

- to complement, and provide a concrete perspective, to existing research on these issues by involving policy makers, stakeholders, and researchers.
- to disseminate knowledge, research, and practices; and contribute to the JPI visibility.

Setting:

The process consists of 4 workshops and is based on a redline document. All workshops will be attended by the whole group of stakeholders, researchers, and policy representatives. During each workshop one group gives its views on the redline document and after each workshop the document is revised. The process ends with a half day face to face event during the participants make a synthesis of all the input and agree on needs for the future.

WORKSHOP 1: Stakeholders

Chair: Nathalie Noupadja (Chair of societal advisory board of JPI MYBL)

PART 1 – Introduction

- About JPI MYBL: aim, activities, agenda (Peter Allebeck, Chair of JPIMYBL)
- Introduction to the topic and aim of the knowledge sharing process (Bruno Arpino, chair of knowledge and sharing activities)

PART 2

- The stakeholders will present their views on the redline document

PART 3

Discussant: Johan Fritzell (chair of scientific advisory board of JPI MYBL)

- Discuss the challenges and actions identified by the stakeholders

Participants who confirmed attendance are

Clemens	Tesch-Roemer	German Centre of Gerontology (DZA)	Germany
Theo	Van Tilburg	Vrije Universiteit Amsterdam	Nederland
Giovanni	Lamura	INRCA IRCCS - National Institute of Health and Science on Ageing	Italy
Elsa	Perdrix	Dauphine University	France
Heidrun	Mollenkopf	AGE Platform Europe	Belgium
Elke	Tippelmann	BAGSO e.V.	Germany
Tineke	Fokkema	Netherlands Interdisciplinary Demographic Institute (NIDI)	
Jennifer	Bethell	KITE Research Institute, Toronto Rehabilitation Institute – University Health Network	Canada
Christina	Victor	Brunel University London	United Kingdom
Annemie	Drieskens	Coface Families Europe	Belgium
Denice	Moi Thuk Shung	ZonMw	Netherlands
Oliver	Huxhold	German Centre of Gerontology (DZA)	Germany
Vincent	Horn	University of Mainz	Germany

Annex II - presentations workshop 1

Knowledge sharing process

"Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Workshop 1. Stakeholders
Mrs. Heidrun Mollenkopf

Are my issues or topics covered?

- o The Redline document is a rather comprehensive document.
- o Most of the issues that are important to our member organisations are covered.
- o Most urgent - and at the same time most challenging – is the general attitude towards older persons:
  - ▪ ageist
  - ▪ generalising
  - ▪ paternalistic
  - ▪ not including them in decision making

- o **Missing in the Redline document:**
  addressing the perspective of older persons themselves
- o **Investigating reasons behind differing outcomes.**

What should/ could research address?

- o **Addressing the perspective of older persons themselves and their informal and formal caregivers.**

- o **Investigating reasons behind differing outcomes:**
- o Did increased ageism contribute to more isolation and loneliness among older people?
  - ▪ Which kind of ageism? Exerted by whom? Impact on x? Y?
- o Was the impact of the COVID-19 on isolation, loneliness, ageism and care different across European countries?
  - ▪ Why? What are the reasons for different outcomes?

What should/ could policy make concrete use of?

- o Make use of what is already known – there is already a lot of knowledge – just two examples:

Corona-Konsultationsprozess der Deutschen Vereinigung für Rehabilitation „Teilhabe und Inklusion in Zeiten der SARS-CoV-2-Pandemie – Auswirkungen und Herausforderungen"
Abschlussbericht
Sicherung der Teilhabe während und nach der Pandemie: Problemlagen, Herausforderungen, Handlungsoptionen
DVfR Germany

Impact of the Covid-19 outbreak on informal carers across Europe
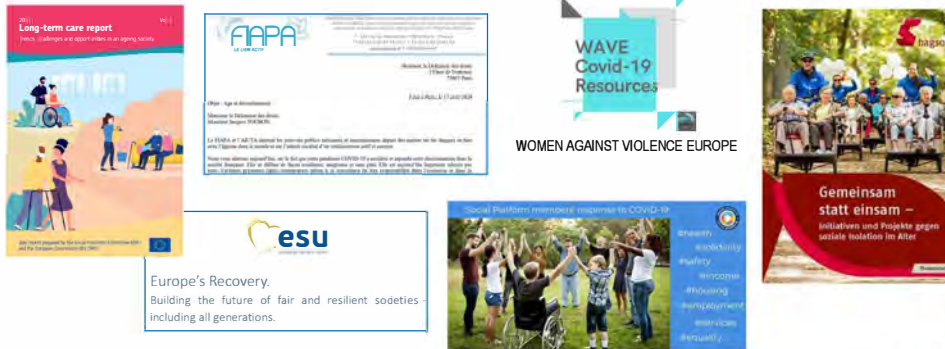Final report

This report presents the findings of an online survey targeted at the informal carers of older, frail or disabled people across Europe regarding their experience during the COVID-19 crisis.

The study, conducted by **Eurocarers** in collaboration with the Italian Institute of Health and Science on Ageing (IRCCS-INRCA), and with the support of the European Commission, builds on 2500 questionnaires submitted by informal carers in 16 countries.

- o Make use of what any further research shows.

Good practices/ examples

WOMEN AGAINST VIOLENCE EUROPE

Europe's Recovery.
Building the future of fair and resilient societies - including all generations.

link with policy priorities in my area

o   All the topics (and more) are linked with both AGE Platform's and BAGSO's mission to voice the interests and needs of older persons

o   We do already use the results of research – and the experiences made and documented by our member organisations

o   **We will of course continue to use new findings.**

o   And what I almost forgot: There were several phases of the pandemic. We have studies originating from the first phase – but how was the development of loneliness and care over time? Did, e.g., the resilience in older persons change to frustration or resignation during the second, third or fourth wave?

Slide 1

JPI MORE YEARS BETTER LIVES

Knowledge sharing process

"Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Workshop 1. Stakeholders

1

Slide 2

JPI MORE YEARS BETTER LIVES

Are my issues or topics covered?

- o If not: which are they?

- o If yes: what would you consider to be the main challenges and the most urgent?

- o Successful approaches in crisis management for vulnerable groups of older people and family carers – criterias / good examples needed

- o *"Emergency care must be provided for these cases at the local level, either through inpatient facilities or through regional "emergency teams" consisting of employees of currently unopened day care and short[1]term care services" (BAGSO position paper)*

21 December 2022   knowledge shairing workshop: stakeholders   2

2

Slide 3

JPI MORE YEARS BETTER LIVES

What should/ could research address?

- focus on the higher-risk populations facing **multiple forms of vulnerabilities**

  - poor health, special health problems such as dementia / depression
  - problems to cover expenses every month
  - living in bad housing conditions
  - No access to internet…

- Focus on **sucess factors**
  - in designing community based services for persons with care needs and family- carers (important actors, methods, role of participation…)

  - Strategies to inform and accompany older people comprehensively in times of crisis

.

21 December 2022   knowledge shairing workshop: stakeholders   3

3

Slide 4

JPI MORE YEARS BETTER LIVES

What should/ could policy make concrete use of?

Development of BAGSO`s work on loneliness on all levels of policy (including the international and European level)

Interreg-project euPrevent PROFILE (Maastricht University) with the general aims to prevent and combat unwanted loneliness in older people.

21 December 2022   knowledge shairing workshop: stakeholders   4

4

Slide 5

JPI MORE YEARS BETTER LIVES

Good practices/ examples

- The project **"Miteinander-Füreinander - Kontakt und Gemeinschaft im Alter"** (Malteser Hilfsdienst e.V)

- *The project is funded by the BMFSFJ. The project is primarily intended to finance the development of new access routes to older and very old people as well as the expansion of voluntary visiting and companionship services. These voluntary services are to be implemented at more than 110 Malteser locations in all federal states.

- During the corona crisis: the Malteser in the diocese of Aachen (one of 27 dioceses) was able to design and implement **new projects** for older people who feel lonely during the Corona pandemic. These include the telephone visitation service , a shopping trolley and the cultural accompaniment service in Aachen- and to recruite **new volunteers**.

21 December 2022   knowledge shairing workshop: stakeholders   5

5

Slide 6

JPI MORE YEARS BETTER LIVES

link with policy priorities in my area

BAGSO, the German National Association of Senior Citizens' Organisations

Through the Secretariat for International Policy on Ageing BAGSO engages in the strengthening of the rights of older people worldwide. *Dr. Mollenkopf (BAGSO) „Germany has a role to play to advance the protection of the rights of older people worldwide."* https://www.bagso.de/english/

Webside on loneliness (DE) : https://www.bagso.de/themen/einsamkeit/

INTERREG, Cross-border cooperation 2021-2023, **Project euPrevent PROFILE (Maastricht University)**

with the general aims to prevent and combat unwanted loneliness in older people. Promoting knowledge exchange between partners (BE, DE, NL) in the Euregio Maas Rhein (EMR)

https://euprevent.eu/profile/

21 December 2022   knowledge shairing workshop: stakeholders   6

6

Slide 1

#BeTheSHIFT

From words to actions:

Shedding light on the S.H.I.F.T. towards meaningful

inclusion in Europe

INCLUSION

Annemie Drieskens

Disability — CoFaCe FAMILIES EUROPE

1

Slide 2

Disability — CoFaCe FAMILIES EUROPE

What is S.H.I.F.T?

5 objectives
Support
Human rights
Independence
Families
Transition

45 actions

15 tools
Person-centred approach
Co-production
Targeted support
Information
Assistive technologies
Complaints procedures
Training
Reasonable accommodation
Partnership
Early intervention
Two-generation approach
Family planning and parental support
Disability mainstreaming
Awareness raising
Regulations on equality

A BETTER SOCIETY FOR ALL FAMILIES

2

Slide 3

Disability — CoFaCe FAMILIES EUROPE

**Support –
transform the disability sector**

Tools to develop the inclusive community based care infrastructures of tomorrow

- **Person-centred approach**: inclusion oriented, community based support, adapted to the wishes and needs of all persons with disabilities and their families.
- **Co-production:** recognising persons with disabilities and their families as experts by experience in the design, implementation & evaluation of support services.
- **Targeted support:** aimed at achieving independent living, putting choices & agency at the centre.

➔ EDRS Flagship Initiative: framework for Social Services of Excellence for persons with disabilities.

3

Slide 4

Disability — CoFaCe FAMILIES EUROPE

Foster Human Rights

Tools to raise awareness, foster respect and promote access to Human Rights:

- **Information:** raise awareness & train on the UNCRPD among persons with disabilities their families and the entire society.
- **Assistive technologies:** Harness the potential of assistive technologies and accessible communication to facilitate communication and advance human rights.
- **Monitor the rights:** make sure complaints procedures are available and fully accessible, involve independents bodies in the monitoring of human rights.

➔ EDRS Flagship Initiative on Accessible EU.

4

Improve Independence

Tools to reshape the mainstream sector to be fully accessible & inclusive:

- **Trainings on Inclusion** for mainstream sector professionals and disability sector professionals to boost independent living in all areas of life.
- **Reasonable accommodations** and equal access in education, employment, health, leisure's, sports… removing barriers form birth to old age.
- **Partnerships:** build bridges between disability and mainstream actors professionals, scale up what works, create cross-sectoral multi level partnerships

➔ EDRS Flagship Initiative on guidance for independent living

5

Empower Families

Tools to empower families, prevent social exclusion & improve social protection:

- **Early intervention and support:** identify and provide early intervention to support family and prevent separation.
- **Two generation approach:** includes the needs of the family members and carers in support assessment.
- **Family planning and parental support** for persons with disabilities, including comprehensive sexual education.

➔ EDRS Initiative on Inclusive Early Childhood Education and Care
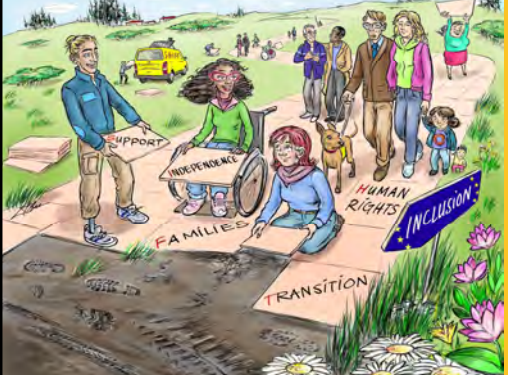
6

Whole Society Transition

Tools to embrace inclusion as core principle, promoting equal opportunities:

- **Mainstreaming disability** across all policy areas
- **Awareness raising** about the benefits of inclusion, informing about different needs and abilities with human dignity at the centre.
- **Regulations on equal participation** in all areas of life by reinforcing anti-discrimination laws and promoting universal design principles in all areas.

➔ EDRS Flagship Initiative the creation of the Disability Platform

7

New report shedding light on the S.H.I.F.T. towards meaningful inclusion in Europe

This collection of 45 practices, real-life examples shows that The S.H.I.F.T. is happening all over Europe and paves the way towards meaningful inclusion.

We hope to encourage and inspire many people to join COFACE's work and #BetheShift."

New report shedding light on the S.H.I.F.T. towards meaningful inclusion in Europe - COFACE Families Europe (coface-eu.org)

COFACE Families Europe is supported by the EU Programme for Employment and Social Innovation "EaSI" (2014-2020). This document is produced with the support of the European Commission but does not necessarily express its views.

8

2

#BeTheSHIFT

Get in touch with us!

COFACE Families Europe
Tel: +32 2 511 41 79
Email: president@coface-eu.org
Website: www.coface-eu.org

Join us on: Twitter **@COFACE_EU**
and Facebook **/COFACE.EU**
and Instagram **familieseurope**

A BETTER SOCIETY FOR ALL FAMILIES

9

3. Workshop 2: Researchers

Stability and change in the associations of risk factors with the development of loneliness across middle and late adulthood: An Analysis based on the German Aging Survey. – Oliver Huxhold

The German Aging Survey showed that the impact of certain risk factors for the development of loneliness may change systematically across the life span. With analyses focusing on shorter time-scales the researchers hoped to demonstrate that these changes in associations also occured in the short-term if there is massive change in contextual conditions (e.g., corona pandemic, widowhood etc.)

Trends and risk factors of loneliness in older adults. – Lena Dahlberg

The Swedish Panel Study of Living Conditions of the Oldest Old and a Systematic review of longitudinal risk factors formed the basis of Lena's presentation. The following five risk factors for loneliness were identified 1. emographic factors; 2. Socio-economic factors; 3. Social factors; 4. Health-related factors; 5. Psychological factors. One of the issues signalled was that some potential risk factors for instance social contact with children, informal care, quality in social relations were not included in longitudinal research performed.

Loneliness before and during the Covid-19 pandemic: prevalence and risk factors among Dutch older adults. – Theo van Tilburg

Theo van Tilburg's presentation highlighted that Combatting social isolation (or few contacts) is not the same as combatting loneliness. They need different approaches. More emphasis should be given to prevention and the though important the role of family shoud not be overestimated. There is also a role for home care helpers and informal contacts. It was also identified that targeted policies reducing the negative impact of vunerabilities. During the pandemic the older adults mostly experienced the 'emptiness' and the diminishing close connectedness with people around them. Many dealt with this by lowering their expectations.

Research review on the association between social connection and health outcomes in longterm care home residents. - Jennifer Bethell

Jennifer Bethell's presentation introduced the participants to the term social connection and defined it as the structural, functional and quality aspects of how individuals connecte to each other. The essential role of social connection in in Long Term Care homes was highlighted during the pandemic. The review also showed that isolation and loneliness were/are important topics in Long Term Care homes before, during and after the COVID-19 pandemic.

Also see Annex 2 for the slides of the individual presentations.

3.1.Conclusion workshop 2

The presentations highlighted the importance of family, friends and other social contacts in preventing loneliness. The stakeholders signalled that the perspective of older persons themselves could be stronger embedded in research.

It also became clear that some research topics, methodologies, and research groups were overlooked in research performed. For example, we miss cross country research; we miss focus on urban, rural differences. These might be very important to understand what kind of welfare state or policy, or practices might reduce the impact of the pandemic or might impact on loneliness in general. So, what we are trying to do during this knowledge sharing process bringing research into policy and practice is very important.

Next steps
- The next workshop will bring the perspective from policy.
- The participants will consider publishing an E-book containing reflections and articles highlighting important findings from the research and the knowledge sharing process. The audience is the general public.

Annex I - List of participants workshop 2

Participants who confirmed attendance are:

Clemens	Tesch-Roemer	German Centre of Gerontology (DZA)	Germany
Theo	Van Tilburg	Vrije Universiteit Amsterdam	Netherlands
Elsa	Perdrix	Dauphine University	France
Heidrun	Mollenkopf	AGE Platform Europe	Belgium
Elke	Tippelmann	BAGSO e.V.	Germany
Tineke	Fokkema	Netherlands Interdisciplinary Demographic Institute (NIDI)	Netherlands
Jennifer	Bethell	KITE Research Institute, Toronto Rehabilitation Institute – University Health Network	Canada
Oliver	Huxhold	German Centre of Gerontology (DZA)	Germany
Vincent	Horn	University of Mainz	Germany
Lena	Dahlberg	Ageing research center	Sweden
Annemie	Drieskens	Coface Families Europe	Belgium

Organisation:

Bruno	Arpino	Coordinator JPI MYBL knowledge sharing Process
Giuseppe	Gabrielli	JPI MYBL General Assembly member
Denice	Moi Thuk Shung	MYBL secretariat
Johan	Fritzell	Moderator & Chair JPI MYBL scientific advisory board
Janice	Keefe	Vice chair JPI MYBL scientific advisory board

Annex II – Programme workshop 2

Draft programme

A knowledge sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Date and time: 10 March 2022 from 14.45 till 18.00H CET.

Organization: Bruno Arpino, Johan Fritzell, Giuseppe Gabrielli

Support and documentation: Denice Moi Thuk Shung and Emma Wilckens, MYBL secretariat

Participants: stakeholders, researchers, and policy representatives

Objectives of the knowledge sharing process:

- to complement, and provide a concrete perspective, to existing research on these issues by involving policy makers, stakeholders, and researchers.
- to disseminate knowledge, research, and practices; and contribute to the JPI visibility.

Setting:

The process consists of 4 workshops and is based on a redline document. All workshops will be attended by the whole group of stakeholders, researchers, and policy representatives. During each workshop one group gives its views on the redline document and after each workshop the document is revised. The process ends with a half day face to face event during which the participants make a synthesis of all the input and agree on needs for the future.

WORKSHOP 2: Researchers

Chair: Johan Fritzell (Chair of the scientific advisory board of JPI MYBL)

Time	
14.45 – 15.00	**Welcome & Introduction**
	- About JPI MYBL: aim, activities, agenda (Johan Fritzell) - Introduction to the topic and aim of the knowledge sharing process (Bruno Arpino, chair of knowledge and sharing activities)
15.00	**Presentation I** **15.00: Oliver Huxhold:** "Stability and change in the associations of risk factors with the development of loneliness across middle and late adulthood - Analysis based on the German Aging Survey."

	15.20: Lena Dahlberg: Trends and risk factors of loneliness in older adults.
15.40 – 15.50	*Screen break*
15.50 – 16.30	**Presentation II** **15.50: Theo van Tilburg:** "Loneliness before and during the COVID-19 pandemic: Prevalence and risk factors among Dutch older adults". **16.10: Jennifer Bethell:** "Research review on the association between social connection and health outcomes in long-term care home residents".
16.20 – 17.45	**Plenary session** Discussant: Bruno Arpino & Johan Fritzell • Comments from the stakeholders. • Discussion of the research questions of the redline document in relation to the presentations.
17.45 – 18.00	**Next steps** (Bruno Arpino)

Annex II - presentations workshop 2

Stability and change in the associations of risk factors with the development of loneliness across middle and late adulthood:
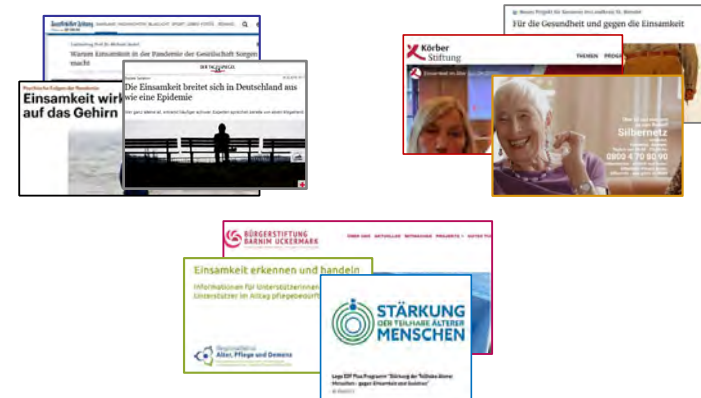An Analysis based on the German Aging Survey.

Oliver Huxhold & Clemens Tesch-Römer
German Centre of Gerontology

JPI-MYBL Knowledge Sharing Process, Workshop 2, March 10. 2022

DZA | Deutsches Zentrum für Altersfragen

1

DZA | Deutsches Zentrum für Altersfragen

Loneliness is a societally relevant topic in Germany

2

DZA | Deutsches Zentrum für Altersfragen

Social Relationships and Loneliness are Core Research Topics at the German Centre of Gerontology

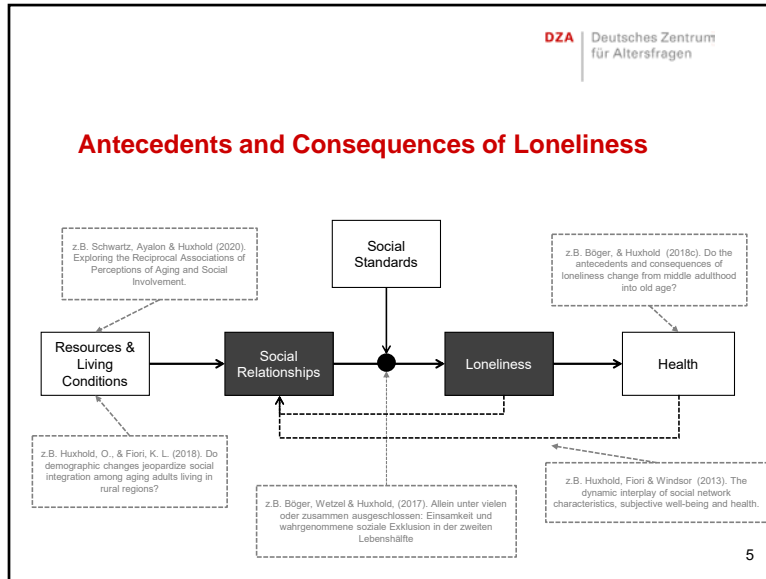
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DZA | Deutsches Zentrum für Altersfragen

A Dynamic Model of Loneliness
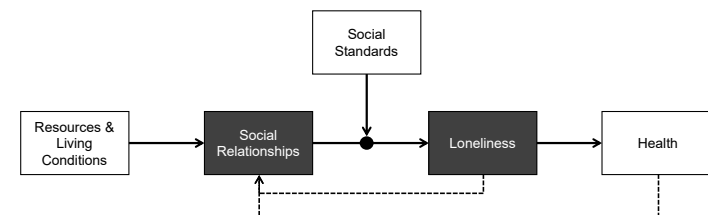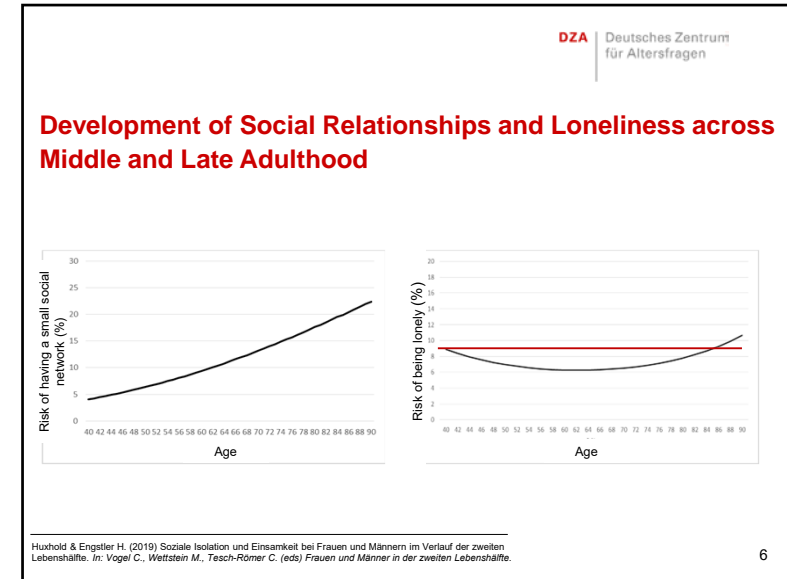

Tesch-Römer & Huxhold (2019). Social isolation and loneliness in old age. *Oxford Research Encyclopedia of Psychology*
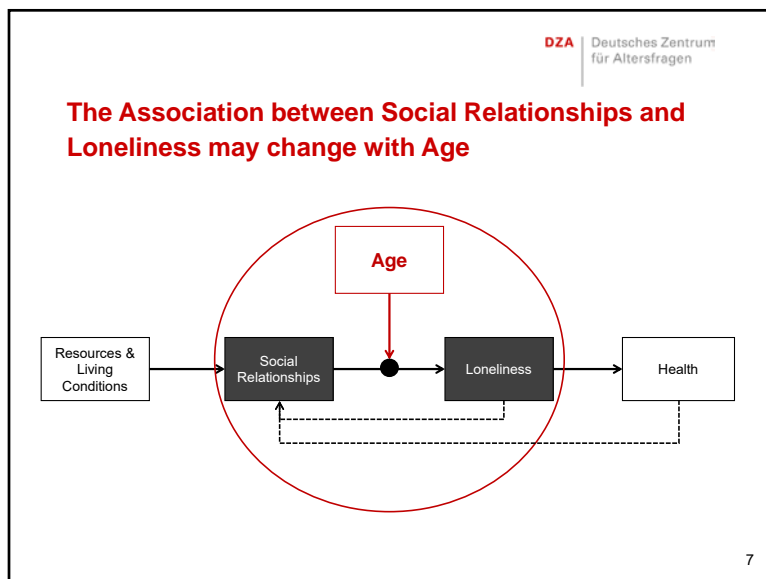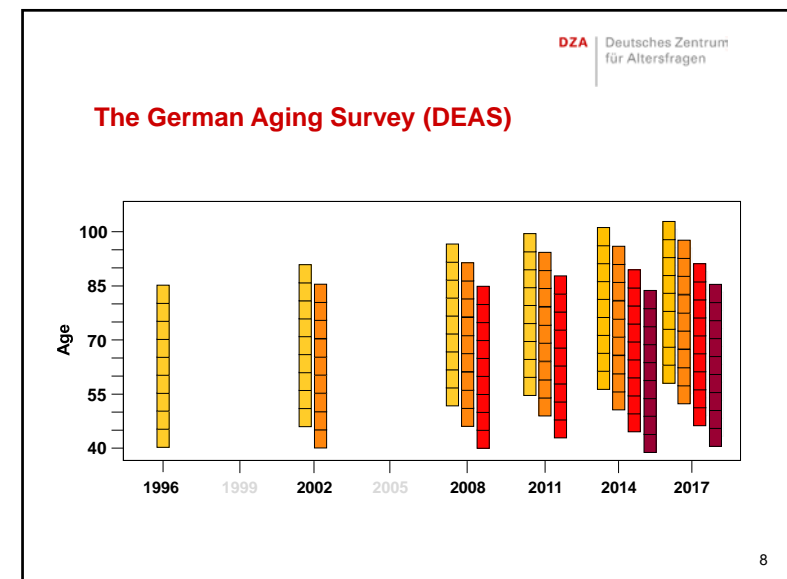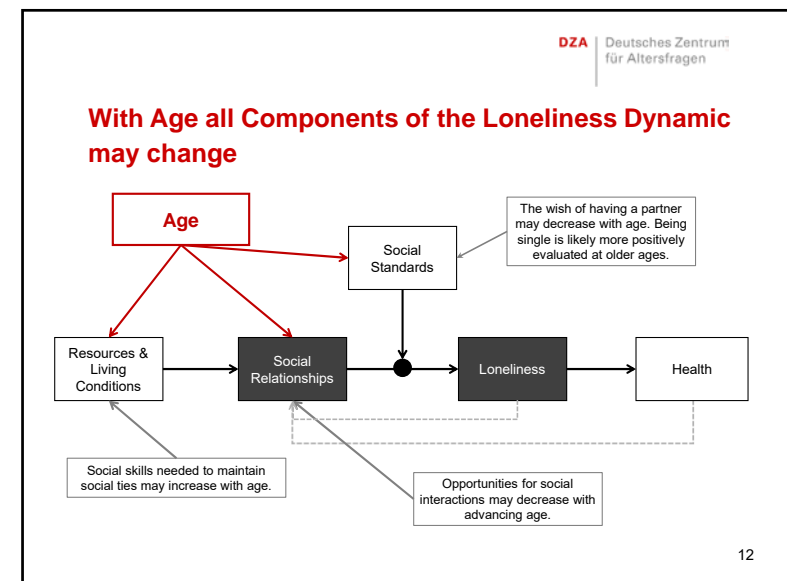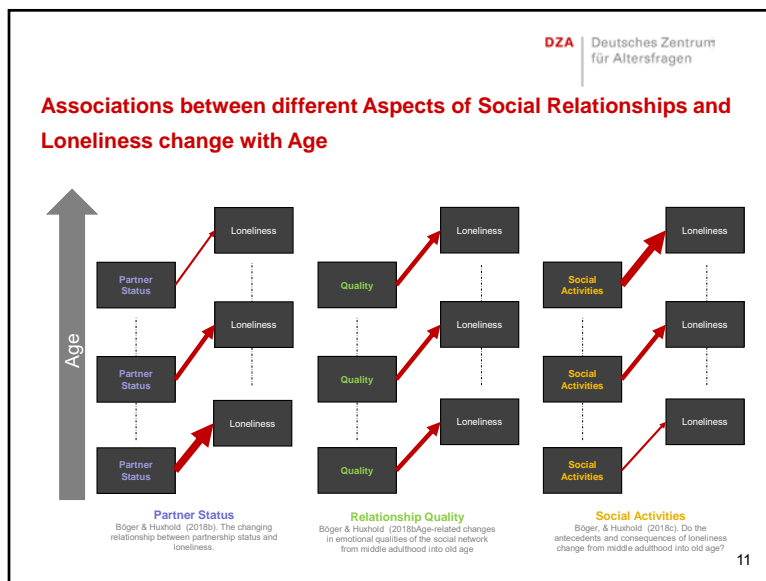
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1

Antecedents and Consequences of Loneliness

Development of Social Relationships and Loneliness across Middle and Late Adulthood

Huxhold & Engstler H. (2019) Soziale Isolation und Einsamkeit bei Frauen und Männern im Verlauf der zweiten Lebenshälfte. *In: Vogel C., Wettstein M., Tesch-Römer C. (eds) Frauen und Männer in der zweiten Lebenshälfte.*

The Association between Social Relationships and Loneliness may change with Age

The German Aging Survey (DEAS)

Using the DEAS for Longitudinal Research on Loneliness
An Accelerated Longitudinal Design: Age as the Measure of Time

Testing with Cross-Lagged Models

Associations between different Aspects of Social Relationships and Loneliness change with Age

With Age all Components of the Loneliness Dynamic may change
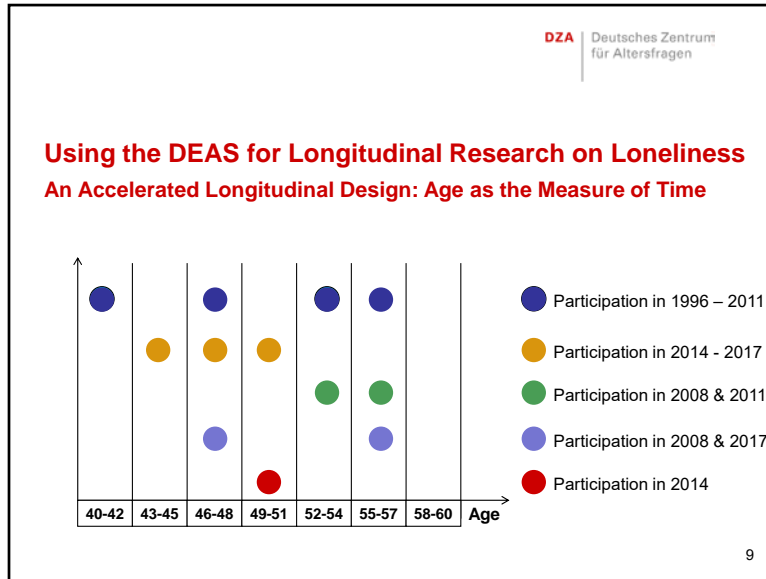
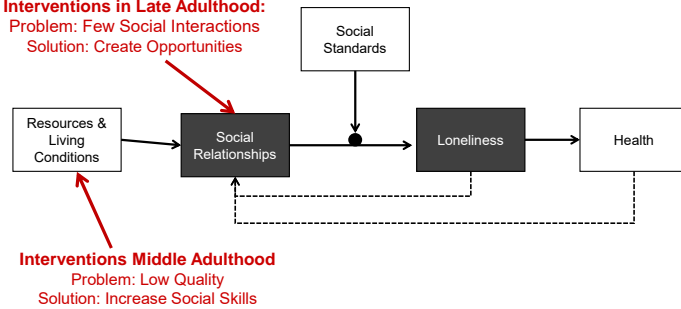**DZA** | Deutsches Zentrum für Altersfragen

Different Interventions for different Phases of Life

Interventions in Late Adulthood:
Problem: Few Social Interactions
Solution: Create Opportunities

Social Standards

Resources & Living Conditions

Social Relationships

Loneliness

Health

Interventions Middle Adulthood
Problem: Low Quality
Solution: Increase Social Skills

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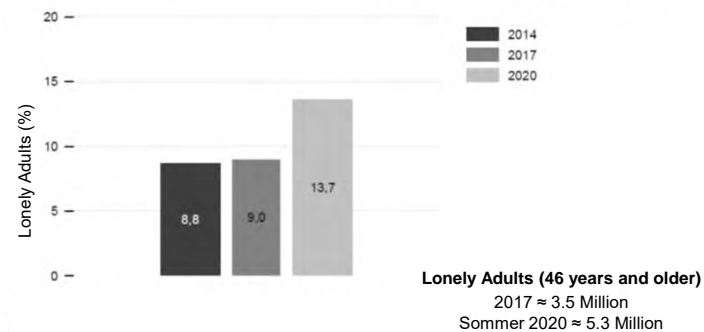**DZA** | Deutsches Zentrum für Altersfragen

Projekt CoESI:
„Consequences of the Corona-Pandemic for the Development of Social Integration in Middle and Late Adulthood"

- Call of the German Federal Ministry of Education and Research "Societal Consequences of the Corona-Pandemic – Research for Integration, Participation and Renewal"

- Selected for the Second Step in the Grant Application in an international Review Process.
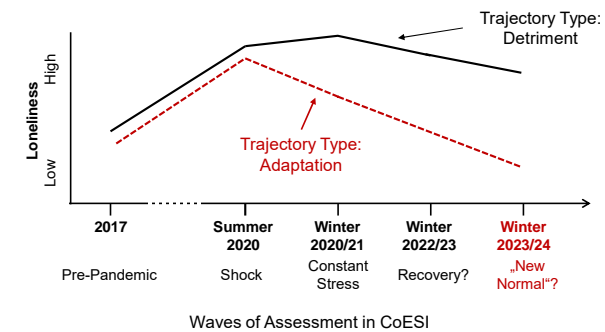
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High Rates of Loneliness in Summer 2020 in Germany

Lonely Adults (%)

2014
2017
2020

8,8 9,0 13,7

Lonely Adults (46 years and older)
2017 ≈ 3.5 Million
Sommer 2020 ≈ 5.3 Million

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Research Perspective: Coping with Loneliness by Adapting to Contextual Conditions

Loneliness (High / Low)

Trajectory Type: Detriment

Trajectory Type: Adaptation

2017	Summer 2020	Winter 2020/21	Winter 2022/23	Winter 2023/24
Pre-Pandemic	Shock	Constant Stress	Recovery?	„New Normal"?

Waves of Assessment in CoESI

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Conclusion

– The impact of certain risk factors for the development of loneliness may change systematically across the life span.

– With analyses focusing on shorter time-scales we hope to demonstrate that these changes in associations also occur in the short-term if there is massive change in contextual conditions (.e.g., corona pandemic, widowhood etc.)

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Thank you for listening!

Stability and change in the associations of risk factors with the development of loneliness across middle and late adulthood:
An Analysis based on the German Aging Survey

Oliver Huxhold & Clemens Tesch-Römer
German Centre of Gerontology

Questions: oliver.huxhold@dza.de

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Literature

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Huxhold, O., & Engstler, H. (2019). Soziale Isolation und Einsamkeit bei Frauen und Männern im Verlauf der zweiten Lebenshälfte. In C. Vogel, M. Wettstein, & C. Tesch-Römer (Eds.), *Frauen und Männer in der zweiten Lebenshälfte: Älterwerden im sozialen Wandel* (pp. 71-89). Springer Fachmedien Wiesbaden. https://doi.org/10.1007/978-3-658-25079-9_5

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Huxhold, O., Fiori, K. L., & Windsor, T. D. (2013). The dynamic interplay of social network characteristics, subjective well-being and health: The costs and benefits of socio-emotional selectivity. *Psychology and Aging*, 28(1), 3-16. https://doi.org/10.1037/a0030170

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Slide 1

Trends and risk factors of loneliness in older adults

Lena Dahlberg

School of Health and Welfare, Dalarna University
&
Aging Research Center, Karolinska Institutet/Stockholm University
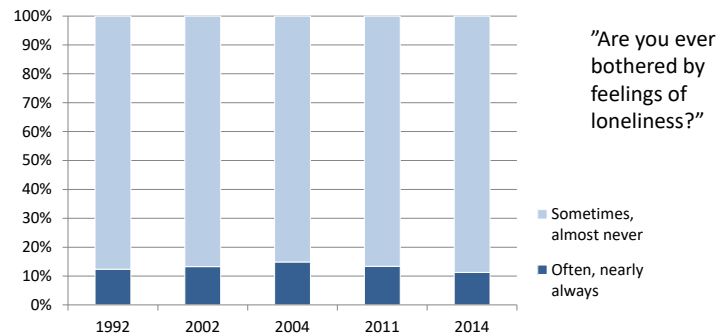
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Slide 2

The Swedish Panel Study of Living Conditions of the Oldest Old

SWEOLD

- Based on the Swedish Level of Living Survey (LNU)
  - Start 1968
  - Random sample of persons living in Sweden aged 18-75 years
- SWEOLD includes LNU-sample aged ~76 years or older
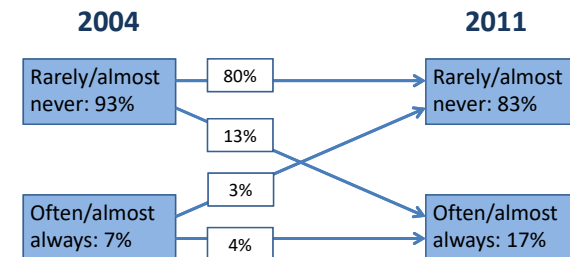- Data collection waves: 1992, 2002, 2004, 2011, 2014
- Ongoing: 2021/2022

2

Slide 3

Trend of loneliness in Sweden (77+)

"Are you ever bothered by feelings of loneliness?"

■ Sometimes, almost never

■ Often, nearly always

(Dahlberg et al., 2018)

3

Slide 4

Change in loneliness over time

2004 → **2011**

- Rarely/almost never: 93%
- Often/almost always: 7%

- 80%
- 13%
- 3%
- 4%

- Rarely/almost never: 83%
- Often/almost always: 17%

(Dahlberg et al., 2015)

4

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Loneliness during the covid-19 pandemic

- Usually convenience samples, online, entire population (there are exceptions!)
  - Older adults underrepresented, rarely separate analyses
  - Older adults are not representative
  - Cross-sectional vs. longitudinal
- Generally: increase (or no change)
- Different contexts – transferable findings?
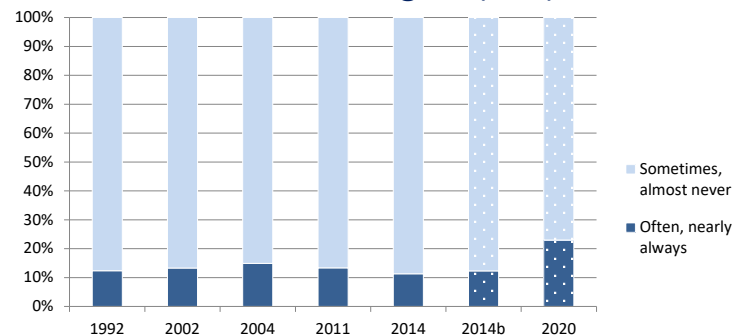
(Dahlberg, 2021; cf. Buecker et al. 2021)

Covid-19 restrictions in Sweden

- Social distancing/isolation of older adults (70+)
- No visits at care homes for older adults
- Loneliness
  - Increase in 70+ year olds, Stockholm region, June-Sept 2020

(von Berens et al., 2021)

Trend of loneliness in Sweden (77+) and Stockholm/urban region (70+)

Legend:
- Sometimes, almost never
- Often, nearly always

(Dahlberg et al., 2018; von Berens et al, 2021)

Systematic review of longitudinal risk factors

- Population: older adults (M=60+ years at follow-up)
- Exposure: any risk factor for loneliness
- Outcome: loneliness
- Study design: quantitative longitudinal
- Setting: high-income countries

(Dahlberg et al., 2022)

Risk factors on loneliness in older adults

- 34 articles
- 120 unique risk factors (i.e., measuring the same construct)
- Many included in one or few articles and/or with mixed results

1. Demographic factors
2. Socio-economic factors
3. Social factors
4. Health-related factors
5. Psychological factors

(Dahlberg et al., 2022)

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Risk factors

1. Demographic factors (n=3)
   - *Age, gender*, ethnicity
2. Socio-economic factors (n=7)
   - E.g. household income, financial situation, education, social status, employment status
3. Social factors (n=58)
   - E.g. **marital partner status**, **limited social network, low level of social activity,** living alone, cohabitation, relationship quality, social support, discrimination

(Dahlberg et al., 2022)

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Risk factors

- Health-related factors (n=23)
  - E.g. **self-perceived health**, various health conditions, cognitive functioning, ADL, IADL, mobility, hearing
- Psychological factors (n=29)
  - E.g. **depression/depressed mood, increase in depression/mood,** self-perceived mental health, anxiety, affect, personality, resilience, perceptions

(Dahlberg et al., 2022)

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Lack of research on risk factors

Potential risk factors not included in longitudinal research, e.g.

- Most aspects of care, e.g., home help
- Social contact with children, informal care, quality in social relations
- Cross-country comparisons, macro-level factors
- Meso-level factors, e.g. urban/rural residency
- Life-course factors

(Dahlberg et al., 2022)

12

Future directions

- Trends in loneliness during and post pandemic
- Risk factors
  - individual risk factors
  - combinations of risk factors
  - contexts of ageing, international comparisons
- Theory, conceptualisation, measurement

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Slide 1

Loneliness before and during the COVID-19 pandemic: Prevalence and risk factors among Dutch older adults

Workshop 2, Discussion on the Red line document (December 3, 2021) prepared for the JPI MYBL knowledge sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care" March 10, 2022

Theo van Tilburg

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1

Slide 2

Older adults more resilient than younger adults?

- Longitudinal Internet studies Social Sciences (LISS)
- Represent Dutch population independently living; age 16–80 (M = 50)
- N = 15,574 with M = 4.9 yearly observations 2008–2021
- Short De Jong Gierveld scales; experiences of emotional or social loneliness

Loneliness type	Emotional	Social
October 2020	High	Low
Age differential	No	No
Age differences	High among younger	High 40-70
Gender	Female > Men	Men > Female
Partner status	Without > Partner	Without > Partner
Years 2008-2021	Increase	

2

Slide 3

Older adults more resilient than younger adults? Loneliness in 1st year of the pandemic

F=6.0*

F=12.4***

No age differential effect (but age differences)

October 2008-2019, 2021   October 2020

— Emotional   — Social

Agreement with ≥1 from three items. Longitudinal Internet studies Social Sciences (LISS) 2008-2021, community dwelling; N_1 = 76,516; N_2 = 15,574; age 16-80; controlled for year, gender, partner status

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Slide 4

Strengths and limitations

- Comparing over many years
- Large age range
- Reliable measurement; two types of loneliness

But
- Infrequent measurement
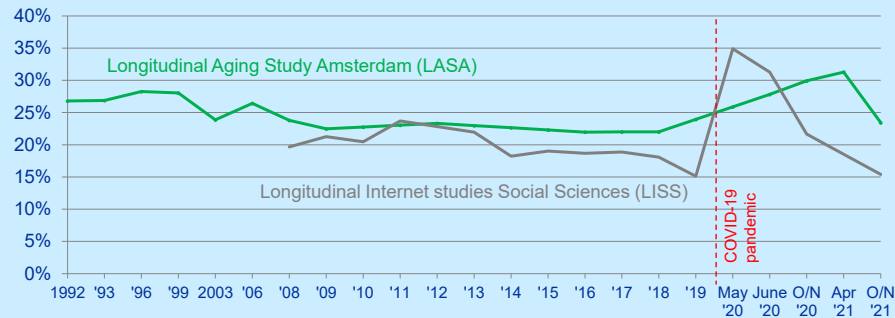- Respondents completed digital questionnaire

4

Slide 5

Emotionally lonely (Dutch; community dwelling; 75+)

Longitudinal Aging Study Amsterdam (LASA)

Longitudinal Internet studies Social Sciences (LISS)

COVID-19 pandemic

Y-axis: 0% 5% 10% 15% 20% 25% 30% 35% 40%
X-axis: 1992 '93 '96 '99 2003 '06 '08 '09 '10 '11 '12 '13 '14 '15 '16 '17 '18 '19 May '20 June '20 O/N '20 Apr '21 O/N '21

Note: different data collection mode and methods. Partially reported (Van Tilburg et al., 2021; Van Tilburg, 2021a,b). LASA: 1-14 items; 146841 item scores; 14369 observations; 3399 respondents. LISS: 6 items; 6918 observations; 1423 respondents.

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Slide 6

Pandemic: 'Social distance', more loneliness?

- Dutch lockdown was not very restrictive - no problem with going outside
  Older people were very active
  Many used communication technology to maintain social contacts remotely
- This may have been sufficient to allow people to cope with the pandemic
- It was not so much social embedding that was affected by the crisis, but rather the 'emptiness' and close connectedness with people around them

Van Tilburg, Steinmetz, Stolte, Van der Roest, & De Vries (2021)

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Slide 7

Pandemic: Regulative coping

Cognitive discrepancy approach to loneliness: lowering relationship standards

- Many people may have seen that others (e.g. in nursing home) were worse off
- Physical distance measures may have lowered expectations of the frequency of contact and exchange in relationships
- More pressure on finding meaning in life? The answer to loneliness has always been to be at peace with oneself. Existential loneliness did not increase
- Many applied active and regulative coping, but those who applied coping had not greater well-being during the COVID-19 pandemic than others

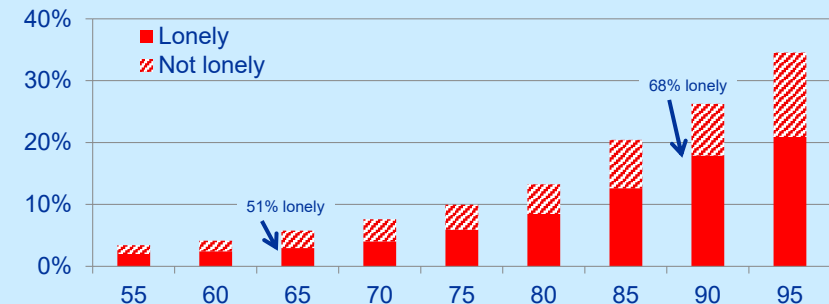Regulative coping contributes to resilience, but is also a threat to future social behavior

Van Tilburg (2021)

7

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7

Slide 8

Share of socially isolated people by age

Isolated = living alone and no weekly network contacts

- Lonely
- Not lonely

68% lonely

51% lonely

Y-axis: 0% 10% 20% 30% 40%
X-axis: 55 60 65 70 75 80 85 90 95

LASA, 1992-2019; N observations = 17581; N respondents = 4965

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Pandemic: Categories at risk

- Increase in emotional loneliness was high for everyone regardless of partner status and having daily network contact
- Protective, before and during the pandemic
  - Higher mastery, better physical functioning protected; resources helped to shape social life
  - Social participation before the pandemic; provides structurally embedded connectedness and social contact
- Protective, before but not during the pandemic
  - Church attendance (online variants did not provide the same level of connectedness)
  - Large social network and having daily contact; less structurally embedded

Van Tilburg (2021)

9

Pandemic and post-pandemic: What to do

- Remind: Combatting social isolation (or few contacts) <> combatting loneliness
- Prevention! Emphasis on structural embedding
  - Incidental social activities may not help or only for a short period of time
  - Do not overestimate role of family: family size is decreasing; daily visits are not always possible; sometimes low quality relationships
    LASA 2019: 37% of 75+ partnerless people at risk (do not have 'important' weekly contact with ≥ 1 relative within 30 minutes travel time)
  - Daily visits by home care helpers and mobilizing latent informal contacts
- Cognitive approach to loneliness
  - Lowering relationship standards: Ageism is also in older adults themselves, making them passive
  - Vulnerabilities are difficult to change; targeted policies can reduce their negative impact

10

Thanks! Questions?
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https://scholar.google.nl/citations?user=VVoZ-ZIAAAAJ

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Publications

- Van Tilburg, T.G. (2021). Emotional, social, and existential loneliness before and during the COVID-19 pandemic: Prevalence and risk factors among Dutch older adults. *The Journals of Gerontology, Series B*. https://doi.org/10.1093/geronb/gbab101
- Van Tilburg, T.G., Steinmetz, S., Stolte, E., Van der Roest, H., & De Vries, D.H. (2021). Loneliness and mental health during the COVID-19 pandemic: A study among Dutch older adults. *The Journals of Gerontology, Series B, 76*, e249-e255. https://doi.org/10.1093/geronb/gbaa111
- Van der Roest, H., Prins, M., van der Velden, C., Steinmetz, S., Stolte, E., Van Tilburg, T.G., & De Vries, D. H. (2020). The impact of COVID-19 measures on well-being of older long-term care facility residents in the Netherlands. *Journal of the American Medical Directors Association (JAMDA), 21*, 1569-1570. https://doi.org/10.1016/j.jamda.2020.09.007

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Slide 1

JPIMYBL Knowledge sharing workshop 2: 10 March 2022

Research review on the association between social connection and health outcomes in long-term care home residents

Jennifer Bethell, PhD

UHN Toronto Rehabilitation Institute | UNIVERSITY OF TORONTO | kite KNOWLEDGE INNOVATION TALENT EVERYWHERE

1

Slide 2

Outline

kite

Answer these four questions:

(1) What is a LTC home?

(2) What are the unique considerations for LTC homes?

(3) What did we already know about social connection in LTC (pre-COVID)?

(4) What happened in LTC homes during COVID-19?

To establish that isolation and loneliness important topics in long-term care (LTC) homes **before**, **during** and **after** the COVID-19 pandemic.

2

Slide 3

kite

"One of the paradoxes of institutional living is the loneliness and isolation of people who are never alone."

Newman ES, Sherman E, Sherman SR. Residential life space: a training session for administrators using the andragogical approach. Long Term Care Health Serv Adm Q. 1978 Sep;2(3):231-7.

3

Slide 4

kite

Social Connection
- structural, functional and quality aspects of how individuals connect to each other[1]
- depends on the existence, roles and qualities of relationships as well as the sense of connection in these relationships[2]

Loneliness
discrepancy between preferred and actual experience of meaningful connections[3-5]

Social Connectedness
opposite of loneliness; extent to which one has meaningful, close, and constructive relationships with others[6]

Subjective

Social Isolation
lack of (or limited) social contact with others

Social Support
actual or perceived resources available from others[7]

Social Engagement
taking part in activities with others[8]

Objective

REFERENCES: 1. National Academy of Sciences (2020) | 2. Holt-Lunstad (2018) | 3. Fried et al (2020) | 4. Prohaska et al (2020) | 5. Perlman & Peplau (1981) | 6. O'Rourke & Sidani (2017) | 7. Cohen & Wills (1985) | 8. Berkman et al (2000)

4

kite

(1) What is a long-term care (LTC) home?

- Sometimes called nursing home, care home

"A nursing home is a facility with a domestic-styled environment that provides 24-hour functional support and care for persons who require assistance with ADLs and who often have complex health needs and increased vulnerability…"

Sanford AM et al. An international definition for "nursing home". J Am Med Dir Assoc. 2015 Mar;16(3):181-4.

5

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kite

(2) What are the unique considerations for LTC homes?

Loneliness (and isolation?) common in LTC:

- Loneliness associated with moving into LTC homes[1]

- Loneliness higher among LTC home residents than other older adults[2]

1. Hanratty B, et al. Loneliness as a risk factor for care home admission in the English Longitudinal Study of Ageing. Age Ageing. 2018;47(6):896-900.
2. Pinquart M & Sorensen A. Influences on Loneliness in Older Adults: A Meta-Analysis, Basic and Applied Social Psychology. 2001;23(4): 245-266.

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kite

(2) What are the unique considerations for LTC homes?

Social connection has multiple meanings in LTC:

- Essential to **quality of life**[1,2]

- Associated with mental[3] and physical[4] **health outcomes**

- A key aspect of **quality of care**[5] and **person-centered care**[6-9]

Yet, (pre-COVID) research and reporting on LTC was critiqued for the focus on medical care and inattention to quality of life, including social connection, as a measure of LTC home quality[10]

REFERENCES: 1. Bradshaw et al (2012) | 2. Moyle et al (2015) |3. Bethell et al (2021) | 4. Lem et al (2022) | 5. Sion et al (2020) | 6. Calkins et al (2018) | 7. Boscart et al (2018) | 8. Fazio et al (2018) | 9. Corazzini et al (2019) | 10. Armstrong et al (2017)

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kite

(2) What are the unique considerations for LTC homes?

LTC residents are a population with unique needs and opportunities for building and maintaining social connection, e.g.,:

- **Residents:** mostly older adults, many with vision or hearing loss, cognitive impairment, and mobility impairment which can impact social connection

- **Families:** many provide vital social support (e.g., participating in care)[1] whereas some residents are unbefriended (incapacitated and have no surrogate decision maker)[2]

- **Staff:** provide daily support to residents, but with limited time and high turnover[3]

- **Homes:** communal setting (e.g., meals, group activities)

- **Communities:** organisations and care professionals participate the life of the home

REFERENCES: 1. Puurveen et al (2018) | 2. Chamberlain et al (2019) | 3. McGilton et al (2020)

8

Slide 9

kite

(3) What did we already know about social connection in LTC (pre-COVID)?

"It is clear….that there is remarkably little research focusing exclusively upon loneliness in care homes either from the quantitative or qualitative perspective."

Victor CR. Loneliness in care homes: a neglected area of research? Aging Health 2012 8:6, 637-646.

9

Slide 10

kite

(3) What did we already know about social connection in LTC (pre-COVID)?

Some emerging evidence on interventions for social connection in LTC:

- Victor (2012)[1]
- Brimelow & Wollin (2017)[2]: 15 (loneliness or social network) intervention studies
- Mikkelsen et al (2019)[3]: 10 (social relations) intervention studies
- Quan et al (2019)[4]: 15 (loneliness) intervention studies in past 10 years

But many intervention studies exclude those with cognitive impairment.

1. Victor CR. Loneliness in care homes: a neglected area of research? Aging Health. 2012.
2. Brimelow RE, Wollin JA. Loneliness in old age: Interventions to curb loneliness in long-term care facilities. Activities, Adaptation & Aging. 2017.
3. Mikkelsen ASB et al. Social Interventions Targeting Social Relations Among Older People at Nursing Homes: A Qualitative Synthesized Systematic Review. Inquiry. 2019.
4. Quan NG et al. A systematic review of interventions for loneliness among older adults living in long-term care facilities. Aging Ment Health. 2019.

10

Slide 11

kite

(3) What did we already know about social connection in LTC (pre-COVID)?

Mental health outcomes (n=61 studies),[1] including:	Physical health outcomes (n=34 studies),[2] including:
Depression	Mortality
Responsive behaviours	Self-rated health
Mood, affect, emotions	Sleep/fatigue
Anxiety	Nutrition/hydration
Cognitive decline	Stress

Bethell J et al. Social Connection in Long-Term Care Homes: A Scoping Review of Published Research on the Mental Health Impacts and Potential Strategies During COVID-19. J Am Med Dir Assoc. 2021 Feb;22(2):228-237.
Lem K et al. Social connection and physical health outcomes among long-term care home residents: a scoping review. BMC Geriatr. 2021 Dec 18;21(1):722.

11

Slide 12

kite

(4) What happened in LTC homes during COVID-19?

"Older people residing in nursing homes have been at a particularly high risk of isolation, loneliness and reduced care received."

- Redline document

12

Slide 13

(4) What happened in LTC homes during COVID-19?

- Sector ignored (gender, ageism, racism, ableism)
- COVID infection and mortality (staff, residents)
- Infection control: resident, family isolation (and the impacts thereof)
- Staffing crisis

Coronavirus crisis shows ableism shapes Canada's long-term care for people with disabilities

Published: May 14, 2020 2:59pm EDT

Years of systemic ageism in health policies contributed to more than 280 Ottawa long-term care residents dying of COVID-19

'Systemic ageism' to blame for COVID-19 deaths in Quebec care homes, inquest hears

COVID-19 crisis in nursing homes is a gender crisis

Women are 90 percent of paid staff in long-term care. Gender must be considered during policy-making, and women must have a seat at the table.

13

Slide 14

(4) What happened in LTC homes during COVID-19?

- Recognition of the vital role that LTC homes and families play in supporting residents - and the need for reform
- Acknowledgement of the importance of measuring and reporting quality of life in LTC homes
- Innovation

14

Slide 15

Summing up:

- Isolation and loneliness were/are important topics in LTC homes **before**, **during** and **after** the COVID-19 pandemic.

- The contexts of LTC residents, families, homes and communities present specific opportunities for addressing isolation and loneliness.

- **COVID-19 highlighted the essential role of social connection in LTC homes.**

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Slide 16

Thank you!

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4. Workshop 3 Policy

Gianpiero Dalla Zuanna: The Italian perspective

It is instructive to observe that every European state – and not just European – has taken different paths, deeply intertwined with the prevailing anthropological structure of families. Moreover, these differences have not disappeared over time, and may, in fact, strengthen in the years to come due to the different demographic dynamics of Northern and Southern Europe. The identification of the most suitable policies to ensure the best possible conditions for seniors should start with a recognition of the profound diversity of family systems across countries. Yet, this does not mean that the welfare of each individual country is definitively shaped by the dominant family configuration. Nor does it mean that countries cannot adapt and change in their search for optimal welfare solutions in a given historical period, looking also at the solutions adopted in other countries.

Elsa Perdix: The French perspective

In France, a governmental loneliness policy is still in development. Before the Covid-19 pandemic, France only had public policies focused on reducing loneliness in elderly. The related activities are organized by associations and charity. The Covid-19 pandemic acted as a catalyst for the government, encouraging them to take action on loneliness (focused on older persons). New initiatives, like intergenerational micro-childcare facilities, were implemented, to fight against isolation, also after lockdown.

Viyeta Biere & Anke Verhoeve: The Dutch perspective

The Dutch government has an action program to combat loneliness among older adults, the slogan is ''one against loneliness'. The program focuses on improving communication on individual level, strengthing aweareness and developed early warning systems. Additionally, it aims to prevent and reduce loneliness, in the long run. This is achieved by (1) communication and a nation wide campaign, (2) establishing a national alliance against loneliness, (3) support of initiatives and interventions, (4) prevention and tackling loneliness on a local level, and (5) science and research. During the Covid-19 pandemic, loneliness levels increased in the Netherlands, and simultaneously social participation decreased. Additionally, awareness of loneliness was raised due to the restrictions.

Christina Victor: The British perspective

The United Kingdom has reviewed several loneliness policies, and they have reframed the definition of loneliness. Their latest strategy was aimed at improving the evidence based burden of loneliness, measurement, and effective interventions. The evaluation of all government strategies and policies regarding loneliness and initiating a national conversation about loneliness. The strategy also aimed at reducing stigma, increasing awareness, and regocnising risk factors. During the Covid-19 pandemic, the UK government launched a major effort to tackle loneliness. For example, budget was cleared for organisations that worked to tackle loneliness and build social connections. Loneliness campaigns in the UK are not only focused on older adults, but on all age categories, which is the prevention component.

See annex 2 for the abstract or slides of the individual presentations.

4.1. Conclusion workshop 3

The presentations showed that loneliness policies differ per country, some are at the start developing their national policies to tackle loneliness, others in the middle of implementing them or reviewing their current policies. Overall it can be concluded that the Covid-19 pandemic really highlighted the issues related to loneliness and isolation and showed the strengths and limitations of the policies and interventions. When it comes to 'curing' loneliness (among older adults), we have a long way to go. For the future it is advised to investigate why some older adults are lonely and some are not, and it use that knowledge the prevent loneliness among all ages.

3. Next steps

The participants will meet again in September to evaluate the knowledge sharing process and to agree on lessons learned and possible recommendation. They are also considering publishing an e-book informing the public about loneliness and isolation from their perspective.

Annex I - List of participants workshop 3

Participants who confirmed attendance are:

Clemens	Tesch-Roemer	German Centre of Gerontology (DZA)	Germany
Theo	Van Tilburg	Vrije Universiteit Amsterdam	Netherlands
Elsa	Perdrix	Dauphine University	France
Jennifer	Bethell	KITE Research Institute, Toronto Rehabilitation Institute – University Health Network	Canada
Oliver	Huxhold	German Centre of Gerontology (DZA)	Germany
Christina	Victor	Brunel University London	The UK
Gianpiero	Dalla Zuanna	University of Padua	Italy
Viyeta	Biere	Dutch ministry of Health	Netherlands
Anke	van Beckhoven	Dutch ministry of Health	Netherlands
Lena	Dahlberg	Ageing research center	Sweden
Tineke	Fokkema	Netherlands Interdisciplinary Demographic Institute (NIDI)	Netherlands

Organisation:

Bruno	Arpino	Coordinator JPI MYBL knowledge sharing Process
Giuseppe	Gabrielli	JPI MYBL General Assembly member
Denice	Moi Thuk Shung	JPI MYBL secretariat
Emma	Wilckens	JPI MYBL secretariat

Annex II – Programme workshop 3

Draft programme

A knowledge sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Date and time: 17 May 2022 from 13.30 till 16.00H CEST.

Organization: Bruno Arpino, Peter Allebeck, Giuseppe Gabrielli

Support and documentation: Denice Moi Thuk Shung and Emma Wilckens, MYBL secretariat

Participants: stakeholders, researchers, and policy representatives

Objectives of the knowledge sharing process:

- to complement, and provide a concrete perspective, to existing research on these issues by involving policy makers, stakeholders, and researchers.
- to disseminate knowledge, research, and practices; and contribute to the JPI visibility.

Setting:

The process consists of 4 workshops and is based on a redline document. All workshops will be attended by the whole group of stakeholders, researchers, and policy representatives. During each workshop one group gives its views on the redline document and after each workshop the document is revised. The process ends with a half day face to face event during which the participants make a synthesis of all the input and agree on needs for the future.

Workshop 3: Policy

Chair: Peter Allebeck (Chair of the JPI MYBL) and Bruno Arpino (Coordinator of knowledge sharing activities)

Time	
13.30 – 13.45	**Welcome & Introduction** • About JPI MYBL: aim, activities, agenda (Peter Allebeck) • Introduction to the topic and aim of the knowledge sharing process (Bruno Arpino, coordinator of knowledge sharing activities)
13.45	**Presentation I** **13.45: Gianpiero Dalla Zuanna**: The Italian perspective **14.05: Elsa Perdix**: The French perspective
14.25 – 14.40	*Screen break*
14.40 – 15.20	**Presentation II** **14.40: Viyeta Biere & Anke Verhoeve:** The Dutch perspective **15.00: Christina Victor:** The British perspective
15.20 – 15.50	**Plenary session** Discussant: Bruno Arpino • Discussion of the research questions of the redline document in relation to the presentations.
15.50 – 16.00	**Next steps** (Bruno Arpino)

Annex II - presentations workshop 3

Gianpiero Dalla Zuanna: The Italian perspective

It is neither easy, nor perhaps useful, to say whether the welfare state was born in Northern and Central Europe to make up for the shortcomings of family aid, or if Eastern and Southern Europe's provision of insufficient welfare has forced families to provide primary assistance to the vulnerable. It is, however, instructive to observe that every European state – and not just European – has taken different paths, deeply intertwined with the prevailing anthropological structure of families. Moreover, these differences have not disappeared over time, and may, in fact, strengthen in the years to come due to the different demographic dynamics of Northern and Southern Europe.

Any broad judgments of the merits of a given welfare system compared to any other must therefore be made with caution. It is unlikely that the welfare approaches of Denmark or Sweden – who have "weak" family ties – would be able to maximize well-being for the frail elderly living in Spain and Italy – who have "strong" family ties. The identification of the most suitable policies to ensure the best possible conditions for seniors should start with a recognition of the profound diversity of family systems across countries. For example, in today's Italy there would be important reforms of the methods of employment of foreign domestic workers, for example by simplifying the procedures to allow regular entries from abroad (also thanks to direct agreements with some countries of departure) and hiring in good standing: it was estimated that at least one third of foreign domestic workers do not have a regular contract.

Yet, this does not mean that the welfare of each individual country is definitively shaped by the dominant family configuration. Nor does it mean that countries cannot adapt and change in their search for optimal welfare solutions in a given historical period, looking also at the solutions adopted in other countries. However, the most suitable "formulas" for helping seniors in countries with strong family ties, where most elderly parents and adult children live in close proximity, will look much different than those most appropriate in countries where the majority of parents live far away from their children.

Slide 1

The Netherlands

Action program
As 'One against Loneliness'

Viyeta Biere & Anke van Beckhoven
Ministery of Health, Welfare and Sport

17th May 2022
For more information contact us at sv.biere@minvws.nl /
ap.van.beckhoven@minvws.nl

1

Slide 2

Content

› Introduction: loneliness in the Netherlands

› Action program 'One against Loneliness'

› COVID-19 and loneliness

› Closure: Lessons learned

2

Slide 3

Loneliness in the Netherlands

EEN TEGEN EENZAAMHEID

Dutch population:

In 2020 47% of the dutch population (18 years and older) experienced loneliness. 36% experienced moderate loneliness and 11% experienced severe loneliness

Eenzaamheid komt voor bij

66% 85-plussers
53% Laagopgeleiden
63% Weduwen, weduwnaars

Ernstige eenzaamheid komt voor bij

14% 85-plussers
14% Laagopgeleiden
21% Gescheidenen

Eenzaamheid per GGD-regio 2020

Ernstige eenzaamheid per GGD-regio 2020

Bronnen: Gezondheidsmonitor Volwassenen en Ouderen 2020 GGD'en, CBS en RIVM

Meer informatie
Deze infographic maakt deel uit van Volksgezondheidenzorg.info, een website van het RIVM. Zie ook www.volksgezondheidenzorg.info/onderwerp/eenzaamheid
Publicatiedatum: september 2018; geactualiseerd juni 2021

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Slide 4

EEN TEGEN EENZAAMHEID

One against loneliness

"To break the trend of loneliness among older people in the Netherlands"

Create a social movement with the message: everyone can do something to tackle loneliness

The program is based on 2 action lines:

1. Improve communication on individual level, strengthen awareness and early warning systems

2. Prevent and reduce loneliness, also for the longer term

4

Slide 5

Focus on 5 pillars

1. Communication & nationwide campaign
2. National alliance against loneliness
3. Support initiatives and interventions
4. Prevent and tackle loneliness on a local level
5. Science and research

5

Slide 6
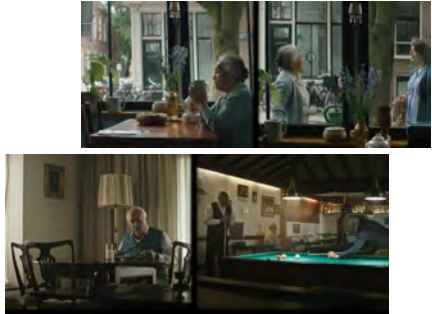
1. Raise awareness on loneliness

- National campaign on tv, radio and internet 'a small gesture can make a difference' Campagne en communicatie - Een tegen eenzaamheid

- National Week against Loneliness

- Website with toolkit and information www.eentegeneenzaamheid.nl → free to download posters, logo 'one against loneliness', tv commercial, factsheets and more products

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Slide 7

2. National Alliance against Loneliness

- More than 160 organisations

2018	2019	2020	2021
65	100	137	166

- Different fields in society: art & culture, sport clubs, religious organisations, supermarkets etc.

7

Slide 8

8

2

Slide 9

EEN TEGEN EENZAAMHEID

3. Support projects and interventions

- Support municipalities, large organisations etc.

- ZonMw program to fund and support projects and interventions
  - More than 120 projects and interventions
  - Help projects in their further development to expand, scale up, evaluate etc.
  - Share knowledge and lessons learned
  - 5.2 million subsidy from One Against Loneliness

ZonMw

9

Slide 10

EEN TEGEN EENZAAMHEID

Lokaal

263

gemeenten geven lokaal een extra impuls aanpak eenzaamheid. Dit doen ze samen met ouderen zelf

75%

In deze 263 gemeenten wonen 1.137.927 75-plussers. Dit is 75% van alle 75-plussers in Nederland

Dit is een stijging met

24%
t.o.v. 2020

VWS ondersteunt gemeenten met een toolkit:
- Signaalpunt tegen Eenzaamheid
- Risicogebieden per wijk in kaart
- Handreiking Huisbezoeken 75+
- Handreiking Ondernemers
- Veelbelovende aanpakken delen
- En 20 adviseurs en een ambassadeur

70 2018 | 128 2019 | 212 2020 | 263 2021

4. Prevent and tackle loneliness on a local level

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Slide 11

EEN TEGEN EENZAAMHEID

5. Science & research

Scientific advisory committee

- Advise to the Minister about monitoring the action program
- Long term science agenda
- Interpreting prevalence of loneliness
- Advise to the Minister about loneliness among young children

HenkSmid
GerineLodder
CretienvanCampen
MaaikeVerhagen
EricSchoenmakers
RickKwekkeboom
TinekeAbmaΩ
AnjaMachielse
TheovanTilburg

National Science Agenda 2022-2024

1. Impact of social distancing on loneliness
2. In what way could we break the taboo
3. How to increase expertise of professionals
4. How can we distinguish existential loneliness of social and emotional loneliness
5. How to decrease loneliness in an effective way
6. How to make chronic loneliness bearable
7. How could we measure loneliness among young people <18.

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Slide 12

EEN TEGEN EENZAAMHEID

COVID-19

Strengthen measures to alleviate impact in 2021 and 2022

- Financial support package for national organisations and municipalities: 200 million

Impact on elderly 75+

- Raised awareness of loneliness due to the restrictions (lockdown etc.)
- Increased level of loneliness among independent living elderly (with and without disability) in 2019-2020
- Decreased level social participation

Source: Nivel, 2021

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Slide 13

Lessons learned

Program level

- Tackling loneliness takes long term approach.
- Support organisations in their approach.
- Involve and connect organisations in different fields.
- Encourage public-private partnerships.
- Invest in strong local networks with various partners.
- Invest in acquiring knowledge, there is still so much to learn about loneliness.
- Make initiatives sustainable for the long term.
- Strengthen a learning approach and practice.

Intervention level – 'what works?'

- Gain insight in own situation
- Improving assessment own capacities
- Learning one's own wishes for the future
- Strengthen grip on life
- Taking initiative

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Slide 14

Thank you for your attention.

Questions?

Visit our website www.eentegeneenzaamheid.nl for more information or send an e-mail to sv.biere@minvws.nl / ap.van.beckhoven@minvws.nl.

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Dauphine | PSL✸

Public Policies to fight against loneliness in France

Elsa Perdrix[1]
elsa.perdrix@dauphine.psl.eu

[1]Université Dauphine, Leda, Legos

JPI More Years Better Lives 13th May 2022

Introduction

Dauphine | PSL✸

Figure 1: Do you feel lonely?

Introduction

Dauphine | PSL✸
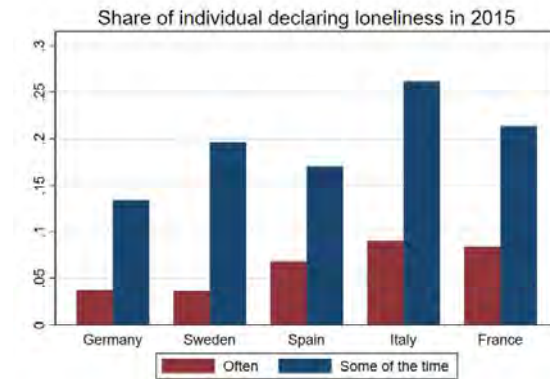
- Two main components of loneliness feelings (Beasley & Perona, 2020)
  - Mental health, wealth, living conditions
  - Social isolation

Introduction

Dauphine | PSL✸

- 9.5% of elderly report seeing once a month or less their relatives
- 35% of elderly would like to have more social interaction
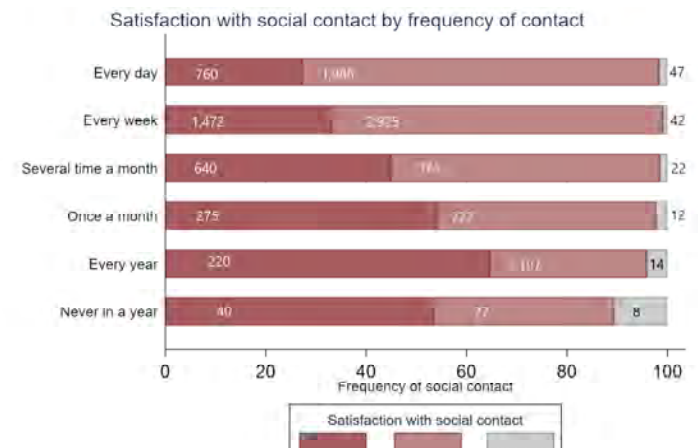
- Public policies for a better mental health
  - Not targeted to specific age groups
  - Includes mostly public health policies
  - Organized by the Government and the Health Ministry, and implemented by each local health autorities
- Public policies fighting against social isolation
  - Targeted to elderly
  - Mostly organized by associations and charity
  - The Government only act as a guide and a coordinator between all these associations

A few example:

- 2011: Loneliness is defined as one of the Great National Purpose (Grande cause nationale)
- Implementation of a website page that list associations help in case of loneliness
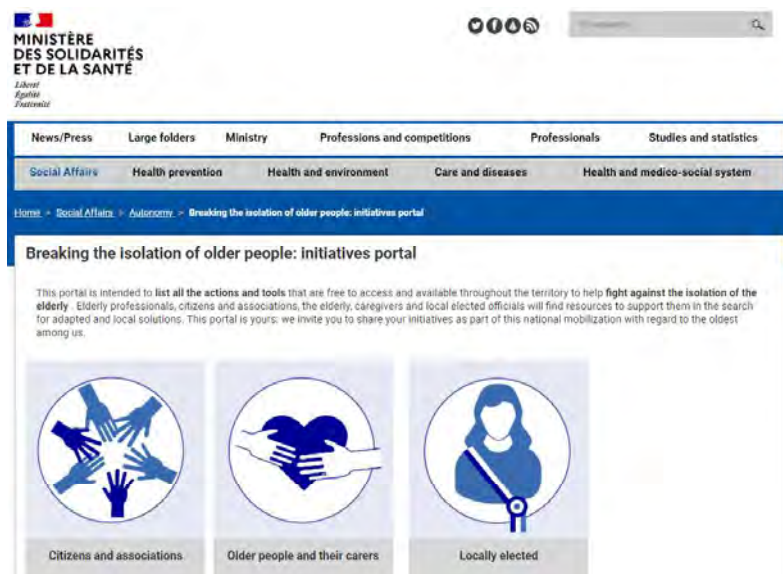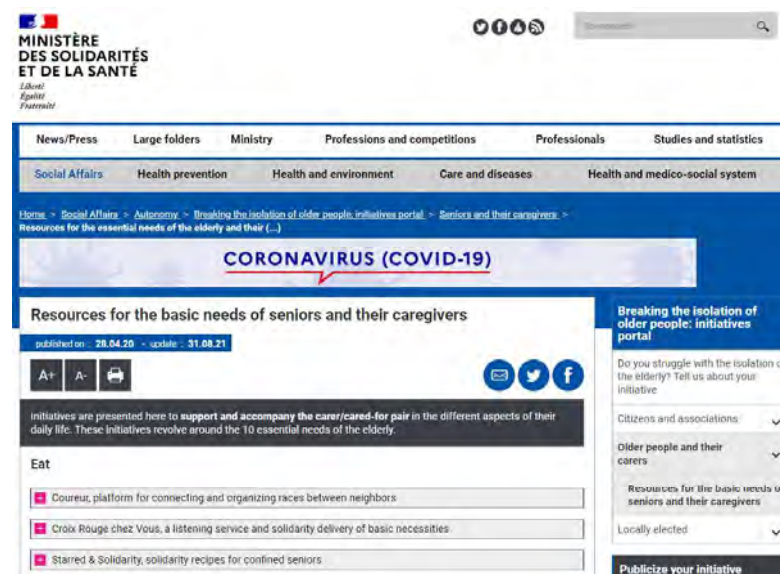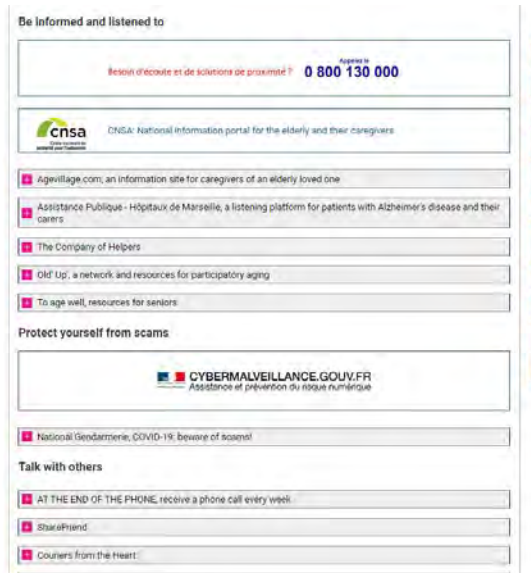
- Intervention of the Government: mostly on housing
- Intervention of Private sector:
  - Complementary health insurance: example of Matmut that implemented Sérélia, a helpline for elderly.
  - La Poste: postman's visit and remote assistance

Changes with the Pandemic? **Ðauphine** | PSL✷

- The pandemic acts as a catalyst
- Media covered a lot the full lockdown in nursing home and the isolation of elderly
- 15th February 2021: Creation of a strategic committee to fight against isolation of elderly
- The Health Ministry asked for information concerning loneliness during the lockdown. This request had been concluded with a report written by J. Guedj, in July 2020 entitled "Not under lock-down anymore but still isolated? Fight against isolation, it is always!"
- Example of new policies: intergenerational micro-childcare facilities

Slide 1

Brunel University London | Institute of Health, Medicine & Environments

UK policy response to loneliness and influence of COVID

Professor Christina R. Victor,
Director, Institute of Health, Medicine and Environments
Professor of Gerontology & Public Health

christina.victor@brunel.ac.uk

Institute of Health, Medicine & Environments

Why did loneliness become a policy problem?
Loneliness strategies in the UK
Evidence & interventions
Have they worked?

Campaign urges barbers to tackle loneliness by offering free haircuts to elderly men

Cookery classes and a call from the postman to stop loneliness

1

Slide 2

Framing Loneliness: a problem of old age

'A distressing feature of old age is loneliness. All who have done welfare work among the old have found it the most common, if at the same time the most imponderable, of the ills from which the aged suffer, and its frequency was amply confirmed by our study"

(Rowntree, 1947,52)

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2

Slide 3

Loneliness a problem of old age

October 18th 2013 the Health Secretary Jeremy Hunt highlighted the **"problem of loneliness that in our busy lives we have utterly failed to confront as a society"** and stated variously that "it **is a source of "national shame"** that as many as 800,000 people in England are "chronically lonely",** ; concluding that **"A forgotten million who live amongst us - ignored to our national shame."**
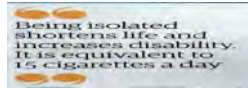
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3

Slide 4

Reframing loneliness-public health/moral panic?

The consequences (of loneliness and isolation among older people) are increasing, unremitting demand on healthcare which will ultimately cripple the NHS." (Keith Willets –Director of Acute Care-NHS England Feb 2016)

1) Prevalence of the condition/exposure (and changes).
2) Impact of the condition on an individual level.
3) Impact on wider society.
4) Condition is identifiable/preventable/treatable

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4

Slide 5

The Jo Cox Commission

JO COX
LONELINESS
start a conversation

Combatting loneliness one conversation at a time

A call to action

Why was she interested in loneliness?
Personal experience?

OUR CALL TO ACTION

We are calling for action from national Government in three key areas:

National leadership
- A UK wide Strategy for Loneliness across all ages
- A nominated lead Minister
- A Family and Relationships Test for new policy

Measuring progress
- A national indicator on loneliness across all ages
- Measures of loneliness included in major national studies
- Annual reporting on loneliness
- A programme to develop the evidence around 'what works' in tackling loneliness
- Easy-to-understand messages to help individuals connect with others and avoid loneliness

Catalysing action
An innovation and spread fund to:
- Stimulate innovation
- Provide seed funding for communities
- Scale-up and spread promising approaches

But it is not just Government that needs to act.
We also believe there is a role for:
- Metro mayors and council leaders
- Public sector leaders
- Business leaders and employers
- Community and voluntary groups

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Slide 6

Loneliness strategies..

Loneliness is one of the greatest public health challenges of our time, Theresa May said today as she launched the first cross-Government strategy to tackle it (Autumn 2018).

A connected society
A strategy for tackling loneliness

A CONNECTED SCOTLAND
Our strategy for tackling social isolation and loneliness and building stronger social connections

May appoints minister to tackle loneliness issues raised by Jo Cox

Tracey Crouch tasked with implementing recommendations from commission set up after the MP's death

Coronavirus: NI executive 'must form loneliness strategy'

9 February 2021

Connected Communities
A strategy for tackling loneliness and social isolation and building stronger social connections

Ministers with responsibility for loneliness in Scotland, Wales & England-

Brunel University London

Slide 7

Strategy aims....

England strategy

Improve evidence base-burden of loneliness, measurement, effective interventions

Embed loneliness evaluation in all govt strategies/policies

Start a national conversation about loneliness, reduce stigma, increase awareness, recognise risk factors,

DANCE LESSONS FOR THE LONELY ON NHS

VISION
A Scotland where individuals and communities are more connected, and everyone has the opportunity to develop meaningful relationships regardless of age, stage, circumstances or identity

PRIMARY VALUES
We are a society which treats all our people with kindness, dignity and compassion

PRIMARY NATIONAL OUTCOMES

| We are healthy and active | We live in communities that are inclusive, empowered, resilient and safe | We grow up loved, safe and protected so that we realise our full potential | We respect, protect and fulfil human rights and live free from discrimination |

PRIMARY NATIONAL INDICATORS

| Places to interact | Loneliness | Child wellbeing and happiness | Children have positive relationships |
| Mental wellbeing | Participation in cultural activity | Confidence of children and young people | Physical activity |

STRATEGIC OUTCOMES

| Understanding increases around social isolation and loneliness and causes/impacts, along with understanding of what works to reduce it | Social isolation and loneliness are reduced | Harm resulting from the effects of social isolation and loneliness is reduced | The conditions which help to reduce social isolation and loneliness are increasingly widespread |

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Slide 8

COVID-19

The government launched a major effort to tackle loneliness during the coronavirus outbreak and period of social distancing. Led by the previous Culture Secretary Oliver Dowden, the plan aimed to ensure that, for people of all ages and backgrounds, staying at home did not need to lead to loneliness.

It included:

- Let's Talk Loneliness public campaign to get people talking openly about loneliness, and guidance on supporting yourself and others safely
- a guaranteed £5 million boost for national organisations working to tackle loneliness and build social connections to help them to continue and adapt their critical work
- Loneliness charities including Age UK were supported to work with NHS Volunteer Responders in their communities
- a network of high-profile charities, businesses and public figures joined 'Tackling Loneliness Network' formed by government to help connect groups at risk of isolation
- the Tackling Loneliness Network published Emerging Together: The Tackling Loneliness Network Action Plan in May 2021, setting out actions for Network members and government to take to tackle loneliness as part of a connected recovery from COVID-19.

Lots of local initiatives

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Slide 9

Better evidence? Measuring loneliness

Recommended national indicators of loneliness

Overview of our recommendations for national measures of loneliness.

Three-item version of UCLA scale

The three-item version of the UCLA scale asks indirectly about loneliness using the following questions:

- How often do you feel that you lack companionship?
- How often do you feel left out?
- How often do you feel isolated from others?

Response categories: "Hardly ever or never", "Some of the time" or "Often".

Direct measure

A single-item measure currently used on the Community Life Survey which asks people directly about their experience of loneliness:

"How often do you feel lonely?"

Response categories: "Often or always", "Some of the time", "Occasionally", "Hardly ever" or "Never".

Box 2: Official Loneliness Measure - Scotland

Single 'indirect' loneliness question:

- How much of the time during the last week have you felt lonely?

Response categories: 'None or almost none of the time', 'Some of the time', 'Most, almost all, or all of the time'

Wales=6 item DJG scale
No single item scale

No agreed measure for NI-uses England measures

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Slide 10

Prevalence of loneliness by age (%) –England 2018

How often do you feel lonely?
% reporting always/often

How well can measures identify lonely people who might benefit from interventions?
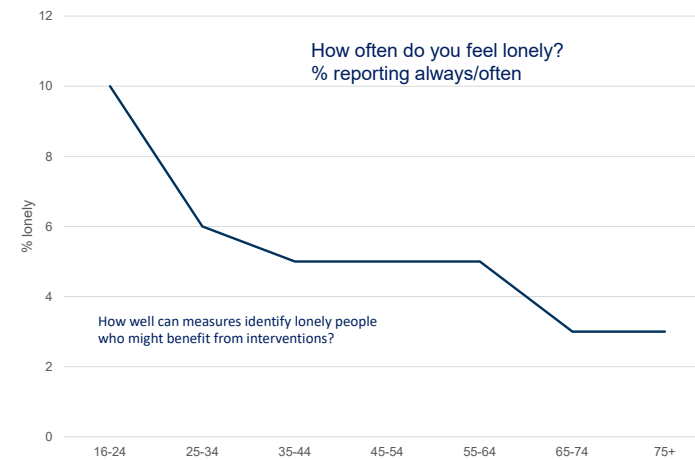
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Slide 11

Loneliness during COVID...increase, decrease, stay the same?

Review of 9 LS studies with pre/during pandemic data showed that:-
2 showed no change, 1 decreased & 6 increased loneliness. Is the change 'significant' and was it due to COVID?

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11

Slide 12

What is the point of loneliness interventions?

Do we want to 'prevent' loneliness in 'at risk' groups and/or reduce or 'cure' the lonely?

Men-in-sheds	Internet groups	Telephone lines	Church attendance	Lifestyle changes	Other hobbies	Libraries
Keeping hens	Arts & culture programs	Friendly-visiting	Singing	Visits from 'postmen'	Talk therapies	Intergeneration programs
Dancing	Education programs (University of 3rd Age)	Communal meals	Pets	Gardening programs	Public awareness through 'badge campaign'	Coffee and cake sessions
Neighbours	Other support groups (e.g. home repairs, snow shovelling)	Transportation programs	Home sharing	Paid and volunteer work	Cookery classes	Bingo, scrabble, bowls

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Slide 13

What loneliness interventions 'work'???

October 2018 — what works wellbeing

An overview of reviews: the effectiveness of interventions to address loneliness at all stages of the life-course

Corresponding Author: Professor Christina Victor

Co-authors: Professor Louise Mansfield, Professor Tess Kay, Professor Norma Daykin, Mr Jack Lane, Ms Lily Grigsby-Duffy, Professor Alan Tomlinson, Professor Catherine Meads

Intervention type	Care homes	Community
Animal therapy	4	
Befriending		7
Physical activity		2
ICT/digital	1	3
Gardening	3	
Relationship advice, support & development		13
Service redesign		2
Psycho-social		5

Key points from review

Small sample sizes: total participants=4658 (study mean=116)

Variety of loneliness measures used and often 'adapted'

Post intervention follow-up rare (6/40 studies reported this and maximum was 12 months (1 study))

Study quality low where it was reported (risk of bias high in 13/20 studies —no studies rated low)

Results from controlled studies in both community and care home settings showed no effect of interventions on loneliness

Focus on individual factors rather than meso/macro-level context?

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13

Slide 14

Questions???

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14

Slide 15

Micro / Individual Level

Risk factors (e.g. widowhood, newcomers, low income seniors, people with poor physical and/or mental health)

Interventions for a 'cure' (e.g. Men-in-sheds, friendly visiting, home sharing, pets)

Loneliness as a synonym for shame, guilt, anxiety, depression, hatred, abandonment, alienated

Challenges among young people and preparation for older age and death

Meso

Absence of participatory approaches to find solutions; community readiness; leadership

Accessibility, cost (e.g. pubic transport, internet)

Macro / Societal Level

Moral regulation or moral panic?

Public health agendas including Age-Friendly World Initiative

UK Loneliness Strategy

The Silent Generation; Baby Boomers; Generation X; Millennials; Generation Z

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