

International Journal of Ageing and Later Life

Volume 17, No. 1, 2023/2024

Published with the support of the Swedish
Research Council (2023-00394)

ISSN 1652-8670 (www)

URL: <http://ijal.se>

Copyright

International Journal of Ageing and Later Life is published under the auspices of Linköping University Electronic Press. All Authors retain the copyright of their articles.

The publishers will keep this document online on the Internet – or its possible replacement – for a considerable time from the date of publication barring exceptional circumstances.

The online availability of the document implies a permanent permission for anyone to read, to download, to print out single copies for your own use and to use it unchanged for any non-commercial research and educational purpose. Subsequent transfers of copyright cannot revoke this permission. All other uses of the document are conditional on the consent of the copyright owner. The publisher has taken technical and administrative measures to assure authenticity, security and accessibility.

According to intellectual property law the author has the right to be mentioned when his/her work is accessed as described above and to be protected against infringement.

For additional information about the Linköping University Electronic Press and its procedures for publication and for assurance of document integrity, please refer to its www home page: <http://www.ep.liu.se/>.

Editor

Linn Sandberg

Associate Editors

Torbjörn Bildtgård

Cristina Joy Torgé

Magdalena Elmersjö

Editorial Assistant

Cristina Joy Torgé

Founding Editor

Lars Andersson

Editorial Board

Sara Arber, University of Surrey, UK

Jan Baars, University for Humanistics, The Netherlands

Simon Biggs, University of Melbourne, Australia

Sally Bould, University of Delaware, USA

Svein Olav Daatland, Norwegian Social Research (NOVA), Norway

Michael Fine, Macquarie University, Australia

Liliana Gastron, National University of Lujan, Argentina

Jay Gubrium, University of Missouri, USA

Andreas Hoff, Zittau/Görlitz University of Applied Sciences,
Germany

Martin Hyde, Swansea University, Wales, UK

Thérèse Jacobs, University of Antwerp, Belgium

Malcolm Johnson, University of Bristol, UK

Marja Jylhä, University of Tampere, Finland

Stephen Katz, Trent University, Canada

Hans-Joachim von Kondratowitz, German Centre of Gerontology (DZA),
Germany

Giovanni Lamura, Italian National Research Center on Ageing, Italy

Judith Phillips, University of Stirling, Scotland, UK

Chris Phillipson, University of Manchester, UK

Marja Saarenheimo, University of Tampere, Finland

Anneli Sarvimäki, Age Institute, Finland

Nan Stevens, Radboud University, The Netherlands

Christine Swane, EGV, Denmark
Theo van Tilburg, VU University Amsterdam, The Netherlands
Julia Twigg, University of Kent, UK
Lucie Vidovičová, Masaryk University, Czech Republic
Anna Wanka, Goethe-Universität Frankfurt am Main, Germany
Virpi Yläne, Cardiff University, UK

Table of Contents

Articles

Exploring co-research interviews with older adults: reflections on research practices and building connections <i>Hanna-Kaisa Hoppania, Anni Vilkkö & Päivi Topo</i>	1
Vital involvement versus ultimate confusion: two contrasting portrayals of dementia in the movies <i>The Father</i> and <i>Floriade</i> <i>Esther-Lee Marcus & Amir Cohen-Shalev</i>	29
Life events and the experience of quality of life among residents of senior housing in Finland <i>Ann-Louise Sirén, Marjaana Seppänen & Mikaela B. Von Bonsdorff</i>	53

Exploring co-research interviews with older adults: reflections on research practices and building connections

By HANNA-KAISA HOPPANIA¹, ANNI VILKKO² & PÄIVI TOPO³

Abstract

Previous research has not only shown the potential of co-research with older adults but also pointed out the need for further study, for example on evaluation and how connections are forged between participants. To this end, this paper (1) describes and reflects on the development and implementation of a co-research interview methodology in the NGO sector and (2) analyses the experiences of the participants and the role of shared age group and locality. The results show that the structure of having several interviews and training and reflection sessions was the strength of the method. The co-researchers found the project interesting and even empowering. Expressions of shared age group and local knowledge were common in the interviews and helped build connections. The interviewees valued their participation in knowledge-production on issues related to ageing. Recruitment, resourcing and support for co-researchers when faced with difficult situations are some of the themes that require further attention.

¹*Dr. Hanna-Kaisa Hoppania*, Lecturer (Public & Social Policy), School of Political Science and Sociology, University of Galway

²*Dr. Anni Vilkkö*, Docent in Social Policy at the University of Helsinki

³*Dr. Päivi Topo*, Ombudsman for older people, Ombudsman's office, Helsinki

Keywords: co-research, participatory research, participatory methodology, social inclusion, volunteering.

Introduction

In recent years, the ideals of democratising research have become more prominent in research on ageing, with a rich vocabulary developing in the field. Co-production is used as an umbrella term for “participatory,” “emancipatory” and “inclusive” research, where communities are involved in knowledge creation, and/or user involvement is part of the development of social provision (Buffel 2018, 2019). The potential utility of seniors’ participation in co-research focusing on their own well-being and social rights has been assessed to be promising (e.g. Blair & Minkler 2009). The political trend to promote social inclusion is also strengthening, and various policy programmes aim to improve participatory initiatives (e.g. European Social Network 2017). The principle of “nothing about us without us” has long defined disability activism and research and has also been raised by the civic rights movement amongst persons with dementia. The key idea is that individuals with disabilities or dementia should always be included in decision-making related to their service provision, knowledge production and the public discussion that concerns them (e.g. Franits 2005). This approach has recently become more prevalent also in gerontological research on social and healthcare services, well-being and living environment, and methods have been developed to include older people in research projects (e.g. Barnes et al. 2013; Bindels et al. 2014; Buffel 2018; De Donder et al. 2014; Tanner 2019).

This paper is based on a co-research project with older people. We focus on reflecting on the *research approach and the interview method used*, whilst the wider results of the project have been reported elsewhere (Hoppania et al. 2021, 2020). To contribute to the further development of co-research methodology with older people, the aim of this paper is to (1) describe and reflect on the development and implementation of a co-research interview method in the NGO sector and (2) to analyse the experiences of the participants (co-researcher interviewers and interviewees) and the role of shared age group and locality for knowledge production. We discuss and reflect on the findings in light of the concerns raised in earlier research.

We understand co-research as an approach to research where people with characteristics or lived experience relevant to the issues being studied take part in conducting the research, and in our case, the relevancy was connected to age and living in a particular area. The structure of this paper is as follows: we first discuss the previous literature and then present the context and aim of our study, the research design and data and then findings. We conclude with a discussion and the implications of this paper.

Literature Review

According to Tine Buffel, co-research and co-production is a viable method for accessing the expertise and knowledge of older people. It is also an effective means for incorporating the views of seldom heard populations whilst providing a forum for meaningful social engagement and mutual learning between older people and other groups (Buffel 2018). Littlechild et al. (2015) highlight the benefits of the quality of data when older co-researchers interview other older people, where they might communicate better with the interviewees and have experiences in common, and the interviewees might feel more at ease with a “peer” interviewer. Mey and Van Hoven (2019) argue that successful participatory research may achieve social inclusion amongst the participants and have relevance to the local community under study, as well as produce rich data and participate in effecting social change. Likewise, Buffel argues that there is an urgent need for social gerontology to engage more fully with co-research methods to realise aspirations for social justice and empowerment (Buffel 2018: 59; see also Tanner 2019).

But despite these benefits, there are many methodological and ethical questions to tackle (see, e.g. Buffel 2018, 2019; Dewar 2005; Littlechild et al. 2015; Mey & Van Hoven 2019; Tanner 2019). There have been critiques claiming that co-research methods can be tokenistic and, in the worst case, contribute to the oppression of services users (Dewar 2005), or that they can function as a way of legitimising elite knowledge (Mey & Van Hoven 2019). Privileged co-researchers, such as those from more affluent backgrounds, might be unwittingly insensitive to the pressures facing people who experience social exclusion (Buffel 2018), and co-researchers might

not always “have the skills to pick up on significant issues and explore them in depth” (Littlechild et al. 2015: 27). It has also been noted that the research field tends to emphasise the positives of co-research based on retrospective narrative accounts of the process, thus better evaluation processes that include the perspectives of all parties have been called for (Littlechild et al. 2015). Mey and Van Hoven (2019: 332–333) identify three topics demanding more investigation, namely, “co-researcher empowerment, production of knowledge and resource investment.” Tanner (2019) notes that very limited attention has been given to analysis of interactions between co-researchers and participants, as well as to the interview process itself and the unique quality of co-produced interviews. In her analysis of interview interaction, Tanner observes how identity or personal characteristics function as bases to build rapport and mutual understanding, but she indicates “the need for greater attention to *how* connections are forged between co-researchers and participants” (Tanner 2019: 305).

Three literature reviews sum up the state of co-research by identifying its benefits and challenges (see Blair & Minkler 2009; Corrado et al. 2020; James & Buffel 2022). The most critical of these reviews is that of Corrado et al. (2020), who state that there are great power differences between academics and co-researchers, which bring about unequal collaboration and offer restricted roles for co-researchers. Blair and Minkler (2009) discussed the same themes 10 years earlier but were more confident of the promises of co-research, despite its challenges. For our purposes, the latest review article (James & Buffel 2022) is the most comprehensive and also considers the main arguments put forward by Blair and Minkler (2009) and Corrado et al. (2020).

To improve co-research, James and Buffel (2022) suggest focusing on four themes, which we briefly introduce here in relation to our contribution.

First, the myriad roles of co-researchers require attention, and, in particular, more knowledge is needed about the motivations and expectations of the older people who take on this role. In this paper, we examine the experiences of co-researchers based on oral and survey feedback (see also May & Van Hoven 2019: 332–333). The second theme is related to the support that is available and given to co-researchers (James & Buffel 2022: 22). The training of co-researchers is nearly always part of participatory research processes, but James and Buffel (2022) call for more attention to be paid to the communication amongst co-researchers and academic

researchers and on developing ethical practices which consider co-researchers' needs for support. We discuss the practices we developed to address this issue and the challenges we faced. Third, to improve the quality and validity of research, the positionality of the co-researchers and the power relations that arise amongst different parties require further discussion. This includes focusing on the communication that takes place between the interviewer and the interviewee. For example, James and Buffel found that "few projects reported the details of recruitment or characteristics of the co-researchers, whether this changed over the course of the project (i.e. attrition), and if so the reasons why this was the case" (James & Buffel 2022: 22). In this paper, we describe and discuss these aspects of the process in detail. The fourth aspect of improvement relates to the fundamental ideas of co-research as a democratising, emancipatory possibility (James & Buffel 2022: 23–24). To feed this kind of change and the co-ownership of research processes, older people (or any other group that social science research addresses) should be involved in the project from the planning stage through to the final evaluation. We discuss these ideals.

Context

The context of our study is a Finnish development programme *Elämänote* ("Grip of Life") (2018–2021), which was funded by the Funding Centre for Social Welfare and Health Organisations (STEA), which is a state-aid authority. The programme brought together 20 NGOs who run local, regional or national projects aiming at the prevention of social exclusion and helping older adults to live at home independently (see Hoppania et al. 2020). The programme's goals were related to the recognition that to enable people to live at home independently for as long as possible, the forms of support must be adjusted to the varied local circumstances and needs. With an aim to enhance social inclusion, the programme, also recognised the potential of older people themselves to participate in the improvement of their circumstances. The programme thus sought to advance and support a variety of different NGO activities. The activities of the programme spanned the whole country from rural villages to city suburbs, and the target group set by the funder was older adults living in "challenging life situations" such as informal spousal care, loneliness, low income and problems with health and functional ability. The projects

offered accessible social and cultural group activities in the community such as art, exercise or cooking classes, and some of them offered and developed active co-leading roles for the participants. Some projects campaigned against the mistreatment and exploitation of older adults or developed and spread new practices in connection with public services and other actors to improve the security and social inclusion of older people.

In connection with the programme, a research project was set up to with the aim of gaining insight into individual experiences about what strengthens the social inclusion of older people, and what role participation in community projects plays in their lives over time. Longitudinal qualitative interviews were chosen as method, and in line with the aim of the programme to improve the social inclusion of older people, the research was planned as co-research. Central in this knowledge production were volunteer older adults who we trained to interview the older people who participated in the NGO projects, and who were living in the same regions and localities as their interviewees. The experiences, feedback and discussions with the interviewers (co-researchers) are a central source of our reflections here, but we also include some discussion of the interviewees' experiences, based on the interview data. The description of the practicalities of the co-research process is also important, in order to gain insight and reflect on the ideals and challenges of co-research methodology.

Our wider research framework is centred around the concept of social inclusion, understood as pertaining to access to material and immaterial resources in one's own physical and psychosocial environment and society. Central to the individual experience of social inclusion is belonging and social cohesion, in the sense that one is part of a community in some meaningful way (Cordier et al. 2017; Isola et al. 2017; Leemann et al. 2021; Ronzi et al. 2018; Smyth 2017).

Research Design, Participants and Data

For the co-research interview, we developed a conversational approach, drawing on the ideas of active interviewing (Holstein & Gubrium 1995), and theme and narrative interviewing (e.g. Hyvärinen & Löyttyniemi 2005). Epistemologically, we draw on constructo-interpretive approaches (e.g. Curburn & Gormally 2017), which are based on the idea of knowledge as being

situational and relational and which aim to bring out a variety of viewpoints about the phenomenon under scrutiny. Personal lived experiences and connections to the research topic are seen as a resource for research, and co-research design aims to strengthen these elements. The role of the researcher is to interpret the different viewpoints and practice conscious, critical reflexivity about his or her own role and that of the other participants of the research process (Coburn & Gormally 2017). In line with these ideas, the interview was semi-structured and partly co-designed with seven co-researchers participating in the pilot phase (see below) of the study. The interview themes were drawn from the framework of social inclusion.

We trained the interviewers and introduced them to the lists of themes for each interview and suggestions for questions for each theme. The interviewers were advised that they could ask the questions in their own words and follow the conversation, rather than strictly keeping to the order of the themes. We split the interview process into three separate interviews. The first and second interviews were held within a short time span, supplementing each other, and focused on different themes of everyday life, social inclusion and living at home. The third interview was a follow-up interview conducted 10–12 months later.

In total, 87 interviews with 33 interviewees and 26 interviewers were completed. Each co-researcher interviewed the same person three times (see below), and one interviewer interviewed just one person, except in the case of four interviewers who interviewed two or three people. Most of the interviews were completed before the corona pandemic. Some interviews were cancelled because of health reasons, the corona situation or other reasons. Overall, the commitment to participate was very good with few co-researchers dropping out before the end of the project. The mean age of the interviewers was 70, and 75 years for the interviewees. Seventy per cent of the interviewers and 76% of the interviewees were women. The socio-economic background was mixed, with the latest profession of both interviewers and interviewees ranging from day care assistants to receptionists, office managers, IT experts, metal workers, farmers, electricians and so on. Nearly all of the participants were Finnish speaking, but one interviewer and one interviewee were Swedish speakers. The Swedish speaking co-researcher also spoke Finnish and participated in Finnish in the training and reflection sessions but conducted the interviews in Swedish.

The interviews were recorded with a digital voice recorder and transcribed. We used Atlas.ti software in the theme and content analysis of the interview data. To focus on the functioning of the co-research method, this paper is based on relevant parts of the interview-transcripts, oral feedback from the interviewers collected during reflection sessions (researcher notes) and on survey feedback from the interviewers ($n = 16$). We coded all of those instances in the interviews, (1) where either the interviewer or interviewee referred directly or indirectly to the fact that both parties are older adults or of the same generation, (2) where the conversation was about local issues and (3) where the conversation was about participation in the interviews.

The feedback from the interviewers was collected during discussions in reflection sessions (see below) where one of the researchers focused on taking notes. After the pilot phase of the study, we also gathered written feedback from the co-researchers with a survey. Those interviewers who took part in the research after the pilot phase were sent an anonymous survey in which we asked about their expectations and experiences of the whole process using both scaled responses to questions and open questions. These data form the basis of our analysis of interviewer experiences, and we use content analysis to describe and reflect upon this data.

The research institute where the study was carried out (The Age Institute) has committed to follow the ethical guidelines of the Finnish National Board on Research Integrity (TENK 2019) in all research activities. In our study, the national guidelines were followed and applied throughout the process. We sought informed consent from all of the interviewees and interviewers and ensured confidentiality, consent and anonymity by discussing their importance in detail in all training sessions with the co-researchers. All of the participants signed tailored consent forms and had the possibility to ask questions and withdraw their consent to participate at any time.

Findings

In this section, we first describe the research process and the experiences of the participants in the pilot phase and the next phase of the study. This serves to respond to many of the issues that, James and Buffel (2022) note, are often not explained in earlier research. We then analyse the experiences

of the interviewees, and how connections were built between the interviewers and interviewees.

Process Description and Experiences of the Co-researchers in the Pilot Phase of the Study

We started with a pilot study, which was conducted in the Helsinki region, at three locations where the *Elämänote* projects were running in January 2019. The follow-up interviews of the pilot phase were conducted in November 2019. With this group of seven co-researchers, we tested the practicalities of the research, such as how to find and recruit participants, how our invitation letters and consent forms work (i.e. are they clear and informative), whether the training was sufficient to give people the tools to conduct the interviews and whether the interview themes and questions were understandable and relevant. The academic research team included the lead researcher (first author, in their late thirties), a second more senior researcher working in a part-time capacity (second author) and a third more senior researcher working in an advisory role and as a manager of the project (third author).

The co-researchers for the pilot were recruited from a so-called “resident jury” (an informal group of locals gathered to support one of the local projects) and from local pensioners’ associations. A one-page invitation letter was drafted to inform and invite the volunteer interviewers. The recruitment criteria were that they were from the same town as the project, and that they were older adults. The invitation stated that we hoped the co-researchers would be curious about learning something new, have skills to meet new people and listen to them, and could relate to someone in a different life situation. We asked them to commit to the training process and complete the interviews. Seven co-researchers were recruited, comprising of one man and six women.

The interviewees were recruited by the employees of the NGOs running the projects. A one-page invitation letter informed them of the context and goals of the research, the timetables and practicalities, and they would be interviewed by an older person. The only inclusion criteria were that the interviewees had participated in the activities (groups/events) organised by the local *Elämänote* project, and that they were older adults. The NGO employees were directed to ask both men and women

to participate. Seven interviewees were recruited for the pilot, six women and one man.

We met the co-researchers of the pilot four times. The training was held in an easy to reach location in the centre of Helsinki. It started with an introduction to the research project and its goals, and by getting to know one another. Most of the 5-hour session was spent going through the role and tasks of the interviewer, and becoming familiar with the themes and questions of the first interview. Practical advice was given on how to conduct the interviews, and ethical issues and confidentiality were discussed. For example, the danger of both parties already knowing some things and therefore not discussing them explicitly was covered, and the interviewers were instructed to try to be explicit and ask for clarifications. Examples of how to do this were presented. During the training, the co-researchers commented that the semi-structured nature of the interview and the openness and flexibility in how they could discuss the interview themes (cf. Barnes et al. 2013) would be helpful in their interaction with the interviewees. Some co-researchers said that they preferred to use the term “conversation” rather than “interview” when inviting participants. They argued that the word “interview” could make possible older participants think of a more demanding questionnaire or survey interview, which some might find off-putting. They also commented on the style of the interviews in feedback discussions.

The training also covered topics such as how to avoid the usual pitfalls of interviews, and how to proceed in demanding situations. Time was taken to practice the use of the digital recorder. Consent forms ensuring confidentiality were also presented, discussed and signed. Lunch and coffee were served, and travel expenses were covered for several reasons, namely, that we wanted to express our appreciation to the participants for volunteering their time and to also enable less privileged people to participate. Furthermore, the lunch and coffee breaks provided time for informal conversations. The first interviews were conducted within a week of the training, and after that, we met the interviewers for a reflection session, where we discussed the experiences of the first interview and introduced the themes of the second interview. The same co-researcher interviewed the same interviewee twice within 2 to 3 weeks. A third reflection and feedback meeting was organised after the second

interviews, where we discussed the experiences of the second interviews and of the overall process. In co-operation with the co-researchers of the pilot group, we concluded that having two interviews within a short time period functioned well. Hence, the co-researchers supported our intent to arrange the interviews in this way by arguing that it was easier to talk with the interviewees during the second meeting as some rapport had already been established, and both parties were less nervous. The overall theme of social inclusion in conjunction with the open conversational model of the interview also meant that it was possible to refer to the first interview during the second interview. In some cases, this possibility was used. The follow-up interviews were organised for the pilot group in November 2019, 10 months after the first two interviews. Five of our seven co-researchers continued in the process, with one cancelling participation due to illness and another failing to respond to our messages. For the third interview, we again organised a training session before the interview and a reflection meeting afterwards.

Based on the pilot interviews and feedback received during the reflection sessions, we concluded that no largescale changes were necessary when considering the continuation of the research project. Based on the discussions with the pilot group, we made some minor changes to the phrasing of some of the interview questions and emphasised the conversational nature of the interviews in the next phase of inviting participants.

Whilst the co-researchers of the pilot gave valuable feedback about the process and actively discussed its various aspects, we did not get them to reflect much about their own role as interviewers. They did comment on how they managed to cover the interview themes or if they failed to ask the interviewee to give more details about a particular question. But overall, the interviewers were more eager to discuss the person they had interviewed, to talk about what kind of conversation they had had, and what kind of interpersonal relations were formed during the interview. We interpreted this focus on the person of the interviewee to be related to the attitude of the co-researchers to volunteering, as one of the reasons they gave as their motivation to participate was to meet new people. To try to gain a better understanding of the interviewers' experiences, more structured feedback, including a survey, was planned and organised for the co-researchers who were recruited after the pilot.

Process Description and Experiences of the Co-researchers in the Next Phase of the Study

After the pilot, the interviews were expanded to the rest of the country, and training was organised in four large towns in the regions in which the NGO projects were running. Nineteen co-researchers and 26 interviewees participated in this phase of the research. We largely followed the practices developed in the pilot. Due to the geographical span of the projects and resource limitations, we used video calls (via Zoom) and phone calls to discuss the feedback from the second interviews. These calls were organised with the help of the local NGO partners, as we did not require the participants to have a computer or the know-how to use video conference tools. The video calls made the interaction between researchers and interviewers somewhat more formal than in the previous face-to-face communication, and the answers to the questions we posed to the interviewers were shorter. Nevertheless, all of the co-researchers gave feedback about the interviews, although we did not hear the informal dialogue which usually brought a rich variety of viewpoints into the group discussions. As planned, we continued with face-to-face meetings for the training and reflection concerning the third interviews. But due to the corona pandemic, the reflection sessions for some of the last interviews were also conducted individually by phone.

Most of the co-researchers had no previous experience of interviewing or research, but many were active volunteers in the NGO sector prior to participating in this project. When asked about their motivation for being a co-researcher, they underlined the importance of social inclusion in old age, an opportunity to learn new skills, and to do some societally significant work. They also stressed the need for training and support and reflected on the limitations of their own skills. However, their most common worry in advance was how they would manage to use the digital recorder. Whilst the majority of the interviews were conducted successfully, in three interviews (with two co-researchers), the recording failed. Afterwards, many commented with some relief about how the use of the digital recorder had not been so difficult after all.

During the reflection sessions, as in the pilot phase, we asked the co-researchers about their general feelings and thoughts after each interview, how they perceived their own role, whether they thought the location of the interview (in most cases, the interviewee's home) affected the conduct of the interview and whether any difficult questions or themes had

arisen. During the final meeting, we asked them about their experience of the entire process, including the training and reflection sessions. Nearly all of the interviewers reported that they felt at least a little nervous or tense before the first interview. They stated that they were excited about meeting a new person, and nervous about how they would manage to carry out the interview. Most said that the second interview was easier, and in many cases, the third interview was the most relaxed.

In the reflection sessions after the third interview, the co-researchers expressed their satisfaction with having participated in the project, and they were happy that they had gained a new experience and learned how to interview. They further emphasised that they had enjoyed the meetings and discussions with the other interviewers, as well as with the academic researchers, and they said that they appreciated that expenses were covered, and that food was served.

Our interpretation is that the informal conversations over lunch and coffee breaks aided in creating a more relaxed atmosphere for the reflection sessions, which was conducive for open and honest conversation. Some interviewers were also somewhat apologetic about not getting what they thought they should have out of the interviews, and some fretted about missing chances to ask clarifying or follow-up questions. Our interpretation here is that some of the co-researchers had quite high expectations of themselves and the interview process, and as they considered the topic and the goal of the research project to be very important, they wanted to perform well. In the reflection sessions, we discussed these experiences and expectations, and the nature of the type of knowledge we were aiming to create (the epistemological underpinnings). On the other hand, successes in establishing a good connection with the interviewee were also noted, and one co-researcher who interviewed two people noted after the final interview that it “went like a dance,” expressing confidence in his skills as an interviewer and being pleased that he had managed to create a good connection with the interviewee.

There were also some instances where the interviewee had shared some quite intimate and difficult issues and feelings. In our estimation, the co-researchers handled these situations well, displaying social skills and life experience, which showed in the interview data as expressions of empathy and understanding. There was also one interview where the interviewee had a very difficult life situation, and this spilled into the

interview, and the interviewer felt ill at ease. The situation was resolved after the co-researcher received support by discussing the situation with the local NGO project worker (face to face) and with the researchers (by phone) and then carried out the second interview in which the atmosphere was better. This exemplifies the need to have time to reflect and discuss the various experiences that such interviews might produce. In our trainings before the interviews, we included discussions about possible challenging situations and had ample time to reflect on the experiences of the interviews afterwards in group meetings and/or video and phone calls. We also anticipated such difficulties when planning the research themes and questions by including an uplifting question at the end of each interview, which directed attention towards positive issues such as the strengths of the interviewee. We encouraged the co-researchers to contact the lead researcher without hesitation if there was anything they wanted to talk about, and a couple of the co-researchers called the lead researcher after their interviews to discuss their experiences.

The survey feedback was positive and in line with the oral feedback received during the reflection sessions, but yielded little new information. Of course, it might be that those with more critical views did not return the feedback form, even though it was anonymous (19 surveys were sent out and 16 answers were received). The co-researchers reported that they considered their contribution to be significant for the interviewees, who they stated, felt valued and heard. Some of the co-researchers also expressed hopes that the results of the research project would, in the longer term, lead to better ageing policies, and one co-researcher said that they would like to be interviewed in this manner themselves.

Experiences of the Interviewees

The interviewees discussed their experiences of being interviewed when directly asked at the end of the second interview and, in some cases, made comments about their participation during other parts of the interviews. For example, the interviewees commented on the format of the interview(s) and expressed positive surprise at the interview's conversational format:

I was a bit surprised [...] I imagined you'd have one, two, three, four... answer this, answer that.

However, the three interview structures caused bewilderment for some of the interviewees. One wondered if they would have anything more to say after the first interview. They also commented on the interview themes, with some seeming delighted when they learned that the questions were about normal everyday life, and some commenting on how the questions had given them food for thought:

Of course, I couldn't prepare for what you're going to ask. But these were all about life and how life is ... very interesting.

The comments about the questions and themes often overlapped with the interviewees' appraisal of themselves as respondents. Some interviewees wondered whether they succeeded in answering the questions and giving the information that was sought. They also expressed gratitude at being asked to participate, and that someone was interested in their experiences and viewpoints:

I was really pleased that my opinions are appreciated ... somewhere.

Building Connections: Shared Age Group and Localities

Throughout the interviews, there were many direct and indirect references to the fact that both parties lived in the same area and were about the same age or from the same generation. Shared experiences of retirement and changing family relations often came up in the discussions. If the interviewee mentioned being a parent or grandparent, the co-researcher would reveal that they too were a parent or grandparent, and sometimes this led to a discussion on different aspects of having adult children and/or grandchildren. Changing health conditions and various ailments typical of old age were also topics in which the shared life stage came up, such as in this extract where the interviewee had just spoken about his experience in hospital when he had a heart attack:

Interviewer: Are you on heart medication?

Interviewee: Yes.

Interviewer: Do you have other such conditions? Have you for instance had your prostate gland operated on?

Interviewee: Yes

Interviewer: With resection?

Interviewee: Yes, resection.

Interviewer: So you too have experienced these old men's maladies then.

Interviewee: Yeah, all of those.

In this case, both parties were men, which clearly also affected the conversation as they found an experience that they shared related to their sex. It is outside the scope of this paper to thoroughly analyse the gendered nature of the interview interactions, but the relevance of sex/gender would merit further study in the co-research literature. Likewise, in another interview when the interviewee had explained the health issues typical of old age that they had had, the interviewer responded:

I've had something similar - not the same but somehow comparable experiences, so I know a little bit how it affects you or how it feels on a daily level.

There were also references to the fact that both parties had lived through the same times. For instance, they mentioned singers or bands that were popular when they were younger in a way that assumed that the other person would be familiar with them. They discussed how times were after the Second World War, how children were treated differently when they were young, or how the culture was "back in the day."

In this excerpt, both parties mentioned that they were married very young and then discussed how culture around courtship and marriage has since changed:

Interviewee: ... so I didn't really have time for courtship..

Interviewer: ... yes, for youth, kind of? Well, there we have similar [experiences] [...] We are children of our time.

Interviewee: Young people [of today] would laugh at us.

Interviewer: Yes, they would.

There were many instances in the interviews where the interviewers (and sometimes the interviewees) referred to “us older people,” showing that they had in mind the age-specific context of the research and were creating and emphasising a sense of shared reality and lifeworld, even if their individual situations were different. In one interview, this came up in the context of discussing local politics and services, and how older people are not consulted:

Interviewee: ... there was a panel discussion, and not a single older person was interviewed, but [only those who manage our things]. Lots of nice things are organised for us old people, and valuable things, but never did they ask what we'd like - it's the younger people there, they think they know better ...

Interviewer: [... maybe because the generation of our children are more educated than us] they don't understand the world of people our age, where we come from and what we need.

The shared age group also came up when discussing digitalisation and how it has changed and affected the lives of the participants during recent years. Significantly, there was no question about digitalisation in the interview themes, but the co-researchers either asked about it or it came up when discussing everyday life, relationships or problems with services. One interviewee spoke about how she had to learn to use the computer after her husband passed away, and the interviewer refers to “we” in a clear reference to their shared age:

Interviewee: I hadn't had to use the computer [before my husband died]. Now I have to learn everything myself.

Interviewer: Yes. But don't you think this would now be a goal - to learn to use them, because now we must ...

All of the interviewers were at least somewhat familiar with the localities of the study participants. In several interviews, expressions such as “I know the place” or “I'm familiar with the surroundings” were used. Local landmarks were also used to place localities when the interviewee was telling about their life, and the interviewer made it known that these places were familiar to them as well.

The shared experiences of the localities and the understanding of affordances such as local services were woven into the interview discussions. The interviewers shared their local knowledge when the discussion dealt with public transportation, and they shared concerns often voiced by the interviewees relating to the accessibility and affordability of services. Sometimes the co-researchers tried to solve the problems, for example, by giving out contact details for the local service councillor and the service centre, or telling the interviewee about various activities provided by NGOs, municipalities and the church. The co-researchers thus sometimes exceeded their role as interviewers as they actively offered advice whilst helping and encouraging the interviewee to participate. But the expressions that emphasised a familiarity with the local surroundings illustrate that the co-researchers wanted to demonstrate a commonality with the interviewees, and to help them benefit from their taking part in the research interview. In our last reflection session, two co-researchers even said that they had agreed to meet with their interviewee after the interviews, and one of them said he felt that they had established the beginnings of a friendship. We did not anticipate these kinds of developments but suggest that people who participate in a project promoting social inclusion (either as interviewers or interviewees) are possibly in a life situation where they are open to new relationships and reciprocal interaction. Even if this kind of role blurring may in some case raise difficult ethical questions, we did not see it as having affected the interview data but instead interpret it more as a natural process.

In their comments about the interview method, the interviewees sometimes explicitly referred to the importance of talking to someone of approximately the same age:

It feels important that we are about the same age, us, the interviewee and the interviewer. It feels that the interviewer can somehow better understand an age-mate.

Whilst the age differences between interviewer and interviewee were generally not large, a couple of the interview pairs had significant age differences. In one case, the co-researcher raised this in the reflection sessions but concluded that it was not (in his opinion) a problem. However, in another case where the co-researcher raised that he felt somewhat frustrated with the interviews, and that he did not get the kind of answers

that were sought, the age difference was significant, which might have played an influential role.

On the other hand, a closely shared age group and locality does not necessarily produce a sense of connection. One co-researcher described the first interview as being “terrible” and concluded that they were on a completely different wavelength than their interviewee. However, she reported that the second interview was easier to conduct and went better. In several of the reflection sessions, the co-researchers also pointed out that their varied experiences show that in this kind of conversational interview, the personality of the interviewee also makes a difference in how the interview proceeds. They, for example, commented on how the interviewee was “very talkative,” or “took the discussion in their desired direction” or how it was difficult to get them say very much. As mentioned earlier, we discussed these questions of research methodology with the co-researchers in the first training sessions and returned to them if the co-researchers raised questions during the reflection discussions. But broadly speaking, these kind of concerns are not specific to co-research but are more general concerns of informal, conversational research methods.

In one case, the interviewee did not understand the point of a question that the interviewer asked, and the interviewer then became confused himself. Here, the fact that the interviewer was an older volunteer did not help the situation as he was not able to clarify what the question was about. Instead, the interviewer tried to rectify the situation by referring to “the wise ones” (researchers) in charge of the research, who would figure things out for “our benefit” (i.e. older people). This episode offers a good illustration of how the power differences between researchers and co-researchers can seep into the interview communication, even if the researcher is not present.

Discussion and Implications

We have described the development and implementation of a co-research approach and discussed some of practices and details, which, according to James and Buffel (2022) and Tanner (2019), have been lacking in previous research, such as the characteristics of the co-researchers, attrition and how connections are forged between co-researchers and participants.

Overall, our experiences and results are in line with earlier co-research findings with older people, and in particular with the potential of such participatory methods to contribute to knowledge related to the well-being and social inclusion of older people (e.g. Littlechild et al. 2015).

Piloting the training practices, consent forms and interview themes were helpful in improving them. Having two interviews within 2 weeks at the beginning of the process was important in building the confidence of the co-researchers, and fostering connections and discussions in the interviews. Our study suggests that the model of two interviews within 2 weeks could also be considered in co-research without a longitudinal element. According to the feedback from the co-researchers, conducting the training with enough time allocated for practicing with the digital voice recorder and having discussions with other co-researchers and researchers in the reflection meetings were important to keep the co-researchers committed to the process. The open, conversational model of the interview allowed various themes that were relevant to the interviewees to be included in the discussions (Holstein & Gubrium 1995). For example, the importance of digitalisation for the social inclusion of older people was discussed with most interviewees, even though this was not mentioned in our research questions (Hoppania et al. 2020).

The fact that both the co-researchers and the interviewees were older adults came forth in the interviews as references to their shared life course position and generational experiences. In essence, co-researchers are invited to pursue a “generational reflexivity” in becoming aware of one’s generational circumstances (Biggs & Lowenstein 2011) because they were asked to participate precisely as older persons talking to other older persons. Thus, the study design can make the participants conscious of their age, which helps elicit generational reflections and discussions of age-related needs in the interviews. The co-researchers and the interviewees were also living in the same region, town or even neighbourhood, and this shared locality was often referred to explicitly or implicitly in the interview data, as well as in the reflection sessions. Particularly, it aided the conversation concerning the significance of the local circumstances for well-being and social inclusion and helped to establish an understanding between the interviewee and interviewer (Hoppania et al. 2021). So in this way, our study corroborates similar observations that were made by the participants of Buffel’s (2018: 57–58) project about how living locally

results in a deeper understanding and richer data about the age-related issues of the area.

An unexpected feature of the interviews was that the co-researchers sometimes exceeded their role as interviewers, as they sought to advise and assist the interviewee in some manner, or in a few cases even begin a friendship with them. An eagerness to advise and help the interviewees also came up in the research by Bindels et al. (2014), and in line with their reflections, we do not see this as necessarily introducing any bias into the research. These kind of concerns have to be evaluated in the context of each particular research project and its aims. In our case, some of the interviewers were already involved in voluntary activities, and this could explain why, in some cases, they were so eager to try and solve problems that were raised by the interviewees. Whilst this “advising” contributed to the wider goal of empowerment for both parties, it clearly raises potential ethical considerations, in particular if the issues that the interviewee is experiencing are of more serious nature because the informed consent was given for the interview and would not extend to any form of counselling. This emphasises the importance of including a consideration of the possible needs of the interviewees that might come up during the interview in the training (e.g. for counselling), and how to respond to these kinds of situations if they arise.

The co-research method discussed here is in line with the constructo-interpretive approach of knowledge as situational and relational (e.g. Coburn & Gormally 2017), creating knowledge together through co-research. Such a process can aid developing the connection between the interview parties in the production of rich knowledge, and the process can be about learning, growth and even emancipation and the possibilities for new social relations (see also Mey & Van Hoven 2019). In our study, the interview themes and questions about social inclusion were close to everyday life, and in that sense, they were also easy to approach.

The type of co-research presented here is a new form of volunteering in the Finnish NGO-sector. According to the feedback discussions and survey data, it was mainly a positive experience for the co-researchers: they considered the training sufficient, and many mentioned that they learned new things or said that the research topic was interesting and that they were pleased to take part in an important project. During the pilot phase of the study, the co-researchers commented on the methodology, but later,

their role as interviewers remained their main contribution. This was due to the resource and time constraints of the project. However, the co-researchers were provided a possibility to join in a discussion when we presented the main findings of the research project in two seminars. Four of them expressed an interest and participated in a seminar in which they shared their experiences. We also invited the co-researchers to join a newly established network of co-researchers at the Age Institute, which would allow contacting them again for possible new projects.

We succeeded in recruiting an adequate number of co-researchers who committed to the process throughout the data collection period. We conclude that several factors contributed to this end: we were able to define the role of the co-researchers clearly enough and the time required for the tasks; the training was sufficient, and the co-researchers had possibilities to reflect on their experiences; and the themes of the interviews were relevant and important to them. This is in line with earlier research, which emphasises the importance of clear communication and offering time for reflection (Bindels et al. 2014; James & Buffel 2022). But it also offers a contrasting example of how a narrower role for the co-researchers (which is not a strength in terms of the ideals of co-research) can nevertheless work quite well in the context of limited resources, which are typical in co-research (James & Buffel 2022).

The interviewees' commitment to participate was also high throughout the process, and they made positive comments on the interview themes and the style of the interviews. Several of them expressed that they were satisfied that someone was interested in their experiences, and that they could participate in knowledge-production on issues related to ageing. The challenges we encountered had to do with misunderstandings regarding some of the interview questions, issues of "being on a different wavelength" some co-researchers reported concerns about getting "good enough" answers and the technical difficulties they faced with the recorder. There were also some interviews where some questions were dealt with superficially or where some of the themes were not explored in much depth. It is hard to estimate whether these could have been avoided with better training. However, our interpretation is that some of these issues had first to do with different personalities, and some are also situations that professional researchers encounter. In our research design, the structure of several interviews helped to alleviate some of these

challenges, but further in-depth and detailed analyses of interview interactions focusing on these kind of challenges would be useful in future studies on co-research.

Notably, we did not encounter problems related to the differences in privilege, insensitivity concerning social exclusion or the lack of explicitness that are mentioned in earlier research (Buffel 2018; Littelfield et al. 2015). This might be partly explained by the fact that the interviewers and interviewees in our study did not differ much in terms of socio-economic background, and the recruitment process for both interviewees and interviewers was similar. However, even though all participants were over 63 years of age, differences in age between the interviewer and interviewee came up in some of the interviews. This demonstrates the importance of being aware of generational and other age-related issues within the general category of “older people” in gerontological co-research. In general, co-research methods are in many ways laborious and also require an attentiveness from the academic researchers that comes close to the ethnographic tradition. Particularly, the researcher must practice critical reflexivity, continuously consider his or her own role, and adjust and adapt according to the changing situation (Coburn & Gormally 2017; Mey & Van Hoven 2019). In our case, the feedback and discussions that featured during the reflection sessions were key to how the process continued, and to the kind of experience that the co-researchers had.

The main limitation of our study is that the experiences of the interviewees could have been examined in more detail, as we only know about their experiences through what came up during the interviews themselves. The recruitment phase and the role of local NGO partners would also merit more attention, and even though the instructions and materials used were the same in all locations, how the recruitment happened in practice in different locations was left largely unexamined. For example, we do not know if the fact that the research was co-research affected who was willing to participate as interviewee. Based on our discussions with the co-researchers, introducing the interview as a low-threshold conversation with another older person might help in encouraging older people to participate who would typically feel intimidated by participating in research interviews.

Additionally, the problems in communication and understanding that arose during the interviews themselves, and also the cases when

difficult situations caused some degree of worry for the interviewer require further examination. The practical time and resource constraints also meant that in this research, we could not offer more extensive participatory roles to the co-researchers. But we do agree with James and Buffel (2022) that promoting the co-ownership of research processes by opening the whole research project to co-researchers and offering them possibilities to participate in different stages of the process would be ideal.

The co-research methodology differs substantially from other qualitative interview methods and requires detailed consideration when updating research ethics, guidelines and practices. The development of (national) guidelines would be useful, especially regarding remuneration, the rights of co-researchers to (professional) guidance and support in case of possible problems, and in delineating the responsibilities of the co-researcher and researchers in ensuring that the interview is not overwhelming for any party. However, in our study, the co-researchers were very supportive throughout the interviews, and in the transcripts, there are numerous positive moments of peer support and reciprocity, boding well for the transformative and rewarding potential of this research approach in the future.

Corresponding Author

Hanna-Kaisa Hoppania, School of Political Science and Sociology, Áras Moyola, Room 224, School of Political Science & Sociology, University of Galway, Galway, Ireland. Email: hanna-kaisa.hoppania@universityofgalway.ie

Statement of funding

This work was supported by STEA, the Funding Centre for Social Welfare and Health Organisations, which operates in connection with the Finnish Ministry of Social Affairs and Health. The research was conducted as part of the coordination project of The Grip of Life programme (2018–2021, grant number C 4809). The funding body played no role in the design, execution, analysis or interpretation of data or writing of the study.

References

- Barnes, M., Taylor, D. & Ward, L. (2013). Being well enough in old age. *Critical Social Policy* 33(3): 473–493. doi: 10.1177/0261018312471163
- Biggs, S. & Lowenstein, A. (2011). *Generational Intelligence: A Critical Approach to Age Relations*. London: Routledge.
- Bindels, J., Baur, V., Cox, K., Heijing, S. & Abma, T. (2014). Older people as co-researchers: A collaborative journey. *Ageing and Society* 34(6): 951–973. doi: 10.1017/S0144686X12001298
- Blair, T. & Minkler, M. (2009). Participatory action research with older adults: Key principles in practice. *The Gerontologist* 49(5): 651–662. doi: 10.1093/geront/gnp049
- Buffel, T. (2018). Social research and co-production with older people: Developing age-friendly communities. *Journal of Aging Studies* 44: 55–60. doi: 10.1016/j.jaging.2018.01.012
- Buffel, T. (2019). Older coresearchers exploring age-friendly communities: An “Insider” perspective on the benefits and challenges of peer-research. *The Gerontologist* 59(3), 538–548. doi: 10.1093/geront/gnx216
- Coburn, A. & Gormally, S. (2017). Critical reflexivity. *Counterpoints* 483: 111–126. Available on <http://www.jstor.org/stable/45177774> [Accessed March 1, 2021].
- Cordier, R., Milbourn, B., Martin, R., Buchanan, A., Chung, D. & Speyer, R. (2017). A systematic review evaluating the psychometric properties of measures of social inclusion. *PLoS One* 12(6): e0179109. doi: 10.1371/journal.pone.0179109
- Corrado, A. M., Benjamin-Thomas, T. E., McGrath, C., Hand, C. & Laliberte Rudman, D. (2020). Participatory action research with older adults: A critical interpretive synthesis. *The Gerontologist* 60: e413–e427. doi: 10.1093/geront/gnz080
- De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.S., Brosens, D & Verté, E. (2014). Developing evidence-based age-friendly policies: A participatory research project. In *SAGE Research Methods Cases* (pp. 1–14). London: Sage Publications.
- Dewar, B. (2005) Beyond tokenistic involvement of older people in research – A framework for future development and understanding. *Journal of Clinical Nursing* 14: 48–53. doi: 10.1111/j.1365-2702.2005.01162.x

- European Social Network. (2017). Co-production: a powerful approach to social services design. *European Social Network, News*. Available on <https://www.esn-eu.org/news/co-production-powerful-approach-social-services-design> [Accessed January 21, 2021].
- Franits, L. (2005). The issue is – Nothing about us without us: Searching for the narrative of disability. *American Journal of Occupational Therapy* 59: 577–79. doi: 10.5014/ajot.59.5.577
- James, H. & Buffel, T. (2022). Co-research with older people: A systematic literature review. *Ageing and Society*, 1–27. doi: 10.1017/S0144686X21002014
- Holstein, J. & Gubrium, J. (1995). *The Active Interview*. Thousand Oaks: Sage.
- Hoppania, H.-K., Vilkkö, A. & Topo, P. (2020) "Jos mä sit kerran tulen." *Elämänote-ohjelman osallisuustutkimuksen tuloksia, osa 1/2* ["Well if I Come Just Once" – Results of the Social Inclusion Research of the Grip of Life Program, Part 1/2]. Ikäinstituutti/ Age Institute. available on <https://www.ika-instituutti.fi/tuote/jos-ma-sit-kerran-tulen-elamanote-ohjelman-osallisuustutkimuksen-tuloksia-osa-1-2/> [Accessed May 10, 2022].
- Hoppania, H.-K., Vilkkö, A., & Topo, P. (2021). "Se on mukavampi yhdessä tehdä." *Elämänote-ohjelman osallisuustutkimuksen tuloksia, osa 2/2* ["It's Nicer Together" – Results of the Social Inclusion Research of the Grip of Life Program, Part 2/2]. Ikäinstituutti/ Age Institute, available on https://www.ika-instituutti.fi/content/uploads/2021/09/Elamanote-2_172x245_7_VALMIS.pdf [Accessed May 10, 2022].
- Hyvärinen, M. & Löyttyniemi, V. (2005). Kerronnallinen haastattelu. In J. Ruusuvaara & L. Tiittula (eds.), *Haastattelu. Tutkimus, tilanteet ja vuorovaikutus* (pp. 189–222). Tampere: Vastapaino.
- Isola, A. M., Kaartinen, H., Leemann, L., Lääperi, R., Schneider, T., Valtari, S. & Keto-Tokoi, A. (2017). *Mitä Osallisuus on? Osallisuuden viitekehystä rakentamassa*. National Institute of Health and Welfare. Available on: <https://www.julkari.fi/handle/10024/135356> [Accessed January 21, 2021].
- Littlechild, R., Tanner, D. & Hall, K. (2015). Co-research with older people: Perspectives on impact. *Qualitative Social Work* 14(1): 18–35. doi: 10.1177/1473325014556791
- Leemann, L., Martelin, T., Koskinen, S., Härkänen, T. & Isola, A.M. (2021). Development and psychometric evaluation of the experiences of social

- inclusion scale. *Journal of Human Development and Capabilities* 23(3): 400–424. doi: 10.1080/19452829.2021
- Mey, E. & Van Hoven, B. (2019). Managing expectations in participatory research involving older people: What's in it for whom?, *International Journal of Social Research Methodology* 22(3), 323–334. doi: 10.1080/13645579.2018.1563977
- Ronzi, S., Orton, L., Pope, D., Valtorta, N. K., & Bruce, N. G. (2018). What is the impact on health and wellbeing of interventions that foster respect and social inclusion in community-residing older adults? A systematic review of quantitative and qualitative studies. *Systematic Reviews* 7(1): 26. doi: 10.1186/s13643-018-0680-2
- Smyth, J. (2017). *Social Inclusion*. *Oxford Research Encyclopedia of Education*. Available on: <https://oxfordre.com/education/view/10.1093/acrefore/9780190264093.001.0001/acrefore-9780190264093-e-129> [Accessed February 12, 2021].
- Tanner, D. (2019). Opening communicative space: What do co-researchers contribute? *Qualitative Research* 19(3), 292–310. doi: 10.1177/1468794118770076
- TENK. (2019). *Finnish National Board on Research Integrity TENK guidelines 2019*. Publications of the Finnish National Board on Research Integrity TENK 3/2019. Available on: <https://tenk.fi/en/ethical-review> [Accessed January 5, 2021].

Vital involvement versus ultimate confusion: two contrasting portrayals of dementia in *the* movies *The Father* and *Floride*

By ESTHER-LEE MARCUS¹ & AMIR COHEN-SHALEV²

Abstract

This paper addresses the possibility and importance of cinematographic representations of dementia that offer an alternative to its popular medicalized stigma. This is explored by comparing two film adaptations of the same theatrical play by Florian Zeller, *The Father*. While *The Father's* (2020) film version by Zeller himself does not depart from the notion of dementia as a story of decline, Le Guay's *Floride* (2015) focuses on the main character's ability for imaginative storytelling. Through narrative analysis, we demonstrate that while Anthony's confusion in *The Father* is an utterly despairing sign of cognitive decline, that very confusion is a vehicle for playful imagination in *Floride*. The vitality underlying such acts of unbridled imagination, along with a matter-of-fact approach to the interruptions of dementia, challenges the negative, deeply seated stigmas of persons living with dementia. Juxtaposed in this manner, these two adaptations provide a unique opportunity to re-examine the role of popular culture in dementia discourse.

¹Esther-Lee Marcus, Department of Geriatrics, Herzog Medical Center, Faculty of Medicine, Hebrew University of Jerusalem, Jerusalem, Israel

²Amir Cohen-Shalev, Faculty of Society and Arts, Ono Academic College, Nethanya, Israel; currently, independent scholar, 3 Brainin St., Tel Aviv, Israel

Keywords: Alzheimer's disease, creativity in dementia, cultural representations of dementia, film studies, personhood in dementia.

Introduction

Mainstream cinema has, in recent years, often poured smooth and standardized portrayals of dementia onto our screens (Capp 2020; Capstick et al. 2015; Cohen-Shalev & Marcus 2012; Medina 2018). Swinnen (2013: 113–114) contends that those films “typically render the story of a disease in progress that reaches its nadir in the time span of the narrative and use metaphors, such as darkness, to add to the story of decline.” These films often reinforce dominant negative attitudes toward people with dementia (Wearing 2023: 102). Less often, but more noteworthy, are attempts to pursue more complex depictions of this predicament that have become more pervasive with growing life expectancy. Our essay joins those of other scholars (e.g. Medina [2018]), who show how world-cinema films such as *Cortex* (Boukhrief & Moreau 2008), *The Good Herbs* (Novaro 2010), *Poetry* (Chang-dong 2010), *Pandora's Box* (Ustaoglu & Kaygusuz 2008), and *Elizabeth is Missing* (Walsh et al. 2019) depict Alzheimer's disease differently than mainstream films (Cohen-Shalev & Marcus 2012). Films can present an alternative understanding that highlights not the sickness and its stigma but the person living with Alzheimer's at the forefront, as central rather than marginalized characters (Chivers 2011).

In 2020, French playwright Florian Zeller took his successful stage play of 2012, *The Father*, onto the big screen, with widespread critical and public applause (Zeller & Hampton 2020). Yet, *The Father* is not the first film adaptation of the play, but the second. The first adaptation was the largely ignored French film *Floride* (Le Guay et al. 2015), directed by Philip Le Guay, starring the French veteran Jean Rochefort as the father and Sandrine Kiberlain as his daughter. Unfortunately, this first cinematic adaptation of Zeller's play received little critical acclaim and public success outside of France. Zeller disapproved of Le Guay's film, claiming it did not even remotely resemble his play (Beasley 2021), but rather “what helped when I came to make *The Father* was that it showed me exactly what I didn't want to do” (Gilbey 2021). Taking it upon himself to direct

a new screen version had been, possibly, a step toward assuring that the success his play had on stage would repeat itself on the screen.

The Father versus *Floride*: Narrative and Counter-Narrative of Living with Dementia

Cinema, especially mainstream Hollywood cinema, often represents prevalent perceptions of dementia as an unremitting and irreversible personal and familial disaster, packaging together old age, cognitive disintegration, and a fatal identity loss. This is arguably due to the dominant medicalized stigma of dementia (Low & Purwaningrum 2020) and the capitalistic pressures that have created the modern youth-obsessed consumer culture propelled by Hollywood and American mass culture (Addison 2003; Ewen 1976). Books and films about dementia almost all tell a story of progressive decline and death, ending in institutionalization or the death of the person with dementia (Low & Purwaningrum 2020). Feelings commonly associated with dementia are fear, shame, compassion, and guilt, and depictions often result in a sense of social distance (Low & Purwaningrum 2020). Much of the cultural production around dementia reinforces rather than resists stigmatization (Capstick et al. 2015). In highlighting such characteristics of dementia, cinema thus becomes yet another “mask of aging” (Featherstone & Hepworth 1991). Popular films often depict midlife, censored, and stereotypical visions of old age. The schism between the socially and artistically fabricated mask and the actual experience of aging become deeper and deeper, save for a few exceptional examples, which are the focus of this essay. While one could study the cinematic mask of aging from a sociological perspective, questioning our society and its attitudes toward aging, it is also important to ask how particular films can enhance our understanding of and insight into the conditions of old age and especially of living with dementia. Films with an alternative view of people living with dementia can substantiate the recent scholarly challenge of the view that dementia inevitably leads to loss of self (Sabat & Collins 1999) and illustrate the “significant shift from the focus on tragic decline” in the stories we tell ourselves about dementia (Basting 2009: 48). This shift challenges the notion that people who live with dementia, Alzheimer’s,

and other types become hollow shells without a trace of personhood left in them.

Le Guay's adaptation takes such an alternative path. While the octogenarian protagonist's confusion in *The Father* is an utterly despairing sign of a mind lost, that very confusion is a vehicle for playful imagination in *Floride*. Whereas *The Father's* dramatic and psychological vision immerses the viewer in the anguish of its lead character, *Floride* capitalizes on his unimpaired, perhaps even augmented ability for storytelling, whose imaginative qualities are of considerable survival value (Heeschen 2001). The humorous vitality underlying such acts of unbridled imagination, along with a "matter-of-fact" dramatically low-key approach to the disruptions of dementia, introduces a little-recognized dimension of what we call "playful confusion," challenging deeply rooted cultural beliefs of disablement.

The Father is, in essence, a faithful adaptation from the medium of theater to that of film. On the other hand, *Floride* takes advantage of the liberties of adaptation, where the text becomes a pretext, and the change in medium metamorphoses the picture. It results in a change of genre: Le Guay's adaptation thus transforms Zeller's play from a tragic drama to one with an almost comic temperament (sometimes defined by film guides as "a comedy," although one should remember that the concept of comedy has a more complex history than one that simply describes something humorous). While literary and cinematic scholars (Langford 2005) have suggested that genre has a role in shaping and creating meaning, except for specific genres (e.g. Westerns or Gangster), most cinematic genres do not necessarily have well-defined visual cues or iconography. This limitation reveals the fact that there are no uniform parameters for genre delimitation, and any genre film can easily "cross-breed" (Tseng 2017). Genre analysis, therefore, will not be the focus of the ensuing analysis.

"Prize-Winning" with a Price Tag: *The Father's* Reception as a Discourse of Glorification

The Father's plot revolves around Anthony (Sir Anthony Hopkins), a former engineer in his eighties, who does not want to admit that he is

experiencing the first symptoms of dementia. His daughter Anne (Olivia Colman), worried about the deterioration of his condition, entrusts him to one caregiver after the other. Still, each regularly ends up leaving her job due to the man's hostile and annoying attitude. This attitude takes the form among other "embarrassments," of a desire that gradually becomes an obsession: to see his other daughter, Lucy, who had died in an accident years before.

The Father was applauded in both professional and public circles (Rai & Banerjee 2022; Sawicka et al. 2022; Wijdicks 2021). Enthusiastic responses were directed primarily at Hopkins' performance, his costar Olivia Colman, Florian Zeller's direction, Christopher Hampton's script adaptation, and the sophisticated cinematography translating the protagonist's progressive confusion of times and places. These accolades have won *The Father* a couple of Oscars for adapted screenplay and best actor. As for acting prizes, Anthony Hopkins is the most recent in a list of winners, from Robert Hirsch in the original Paris stage production, Kenneth Cranham in London's West End, and Frank Langella on Broadway, among other more local cases. One critic suggested that the figure of the older man with dementia is a-priori destined for eminent actors:

Those who oscillate in the blink of an eye between the powerful and the frail, the charismatic and the extinct, from the delightfully vivid to the tragically fragile, and from the ominous and admirable to the pathetic (Rave 2021).

This ubiquitous enthusiasm is suspect. It raises the possibility of fending off a deeply disturbing anguish at the hero's suffering with the glorification of his theatrical proxy, keeping the devastation of full confrontation with the reality represented on the screen at a safe distance. Keeping the harsh reality at bay is, of course, incongruous with the explicit effort toward total spectator immersion in the mind of a person who lives with dementia, frequently considered the singular psycho-aesthetic achievement of the film (Capp 2021). Immersion can become a double-edged sword, as it stands in the way of reflection. The last scene of *The Father*, perhaps intentionally, ensures that the audience remains securely fastened to the seat belts of immersion through the shocking and shaking experience of Anthony's terminal defeat and his return to dependency. Being powerfully drawn into the hero's emotional distress overshadows

and discourages critical judgment and even de-legitimizes an effort at a more balanced appraisal. Feeling pre-empts thinking. Identifying with the protagonist's predicament excludes other responses and may even induce guilt in failing to emote.

Jean Rochefort's Claude (the equivalent of Anthony) in *Floride* did not win a prize, which makes the distinguished French veteran (this was his last role) an exception to the rule, not attributable to the film's deficiencies (there are a mere few), but more likely to his acting style, reflecting the conception of *Floride* as a whole. Rochefort's approach is the opposite of Anthony Hopkins: understated, un-theatrical, patently and deliberately indeterminate and ambiguous. As much as Hopkins' portrayal is complexly nuanced, it is based on a positively defined diagnosis. His struggle against confusion and forgetfulness is a direct outcome of his neuropsychological condition, and so is his extreme agony, which the audience is supposed to approximate in emulation. His dementia, while it may not be clinically detailed, is a clear-cut categorical "case." The illness threatens his continuous sense of identity, making him half the man he had been until in the end, he becomes the infant he had been. The loss of existential security is under constant assault. Dementia as a primarily medical syndrome is never in question, irrevocably determining the psychological price for both the people living with dementia and their caregivers.

It is exactly this vision of dementia that is questioned and undermined in the course of watching *Floride*. While Anthony Hopkins, as the eponymous protagonist of *The Father*, accentuates in his portrayal the signs of decline associated with the medicalized stigma of dementia, Jean Rochefort, his equivalent in *Floride*, seems to inhabit a liminal subjective territory of accumulative uncertainty. While the infantilized Anthony receives maternal care from a female staff member who promises him a walk in the park later in the day (the camera turns to the window, a shot of the park outside that does not include the protagonist who lives with dementia), Claude goes to the window, looks outside, and says, "I didn't know they had these trees in Florida." Apart from the bitterly comic moment of continued disorientation, he again re-orientates his still extant self in a continued imaginative space that he imports into the new physical space of the nursing institution. It is an act of mental reappropriation of physical reality and, as such, a

proclamation of survival within the closing constraints of the mental condition of dementia, a flight via imagination from the gravitation of progressive dementia.

Floride does not obey the cultural concept of a total loss of self and the unalloyed suffering synonymous with the medicalized trope of “dementia.” Nor does the film take the alternative extreme, the “forget memory” vision (Basting 2009), emphasizing the importance of activities that focus only on the present to improve the lives of persons with dementia. Rochefort’s Claude hovers in an existentially transitional space, making it almost impossible to positively define his status, either medically or psychologically. This particular type of confusion regarding the epistemological status of dementia, rather than the confusion commonly attributed to dementia, may be a bewildering experience for many viewers, including medically oriented scholars, as it challenges deep-seated and widespread perceptions of dementia. It calls for a measure of tolerance of ambiguity that goes against expectations for clearly defined characterizations in cultural products such as films. In an ironic twist, Claude’s well-being, or the very plausibility of well-being in the context of dementia, works against his perceived credibility.

While in no way underplaying the harsh realities of dementia, Claude does not “lose everything,” to quote Zeller (Gilbey 2021). It is at this point that Le Guay departs from the original stage play. In adapting the play to the screen, Le Guay literally leaves the stage, does away with the fourth wall, and opens up the vista to include the world outside in all its variety and Alpine beauty (the film was shot in the environment of Lake Annecy). In contrast, Anthony’s world in *The Father* is limited to the enclosed space/stage of his apartment, and a precariously inconstant and diffused space at that, losing some details while keeping others as his disintegrating mind meanders between the real and the illusory. This difference is also illustrated by the different use of lighting in the two films. *The Father* focuses on the inside of things (in terms of physical and mental space), an inwardness illustrated by a dim twilight reflecting the “dying of the light.” In *Floride*, in contrast, the light flows in and out of the protagonist’s dwelling place. The outdoor scenes were shot in natural light, and the film, on the whole, is brightly lit, illustrating the “bright side” of life under the shadow of dementia.

Immersion: Asset or Liability?

According to Zeller, in an interview with Beasley (2021), the idea of *The Father* was to put the audience in a unique position, as if the audience was going through a labyrinth questioning everything – what is real, what is not real? – as if we were, in a way, in Anthony’s mind. *The Father* thus becomes an exercise in virtual verisimilitude, a double “tour de force”: a performance of acting and production of virtual reality, putting the audience inside the mind of a person who lives with dementia, arguably a futile enterprise since there is no way of really knowing, and since that mind is a-priori culturally constructed (Kitwood 1997).

In the same interview, director Zeller said:

I wanted *The Father* to be not only a story about a man losing his bearings but **an experience** – and the experience **of what it could mean to lose everything** (emphases added), including your own bearings as a viewer (Beasley 2021).

Zeller seems to be interested in people with dementia more as a metaphor for the condition of losing everything. Thus, taking so much trouble to immerse the viewer in the experience of dementia, the intricate mechanism that prompts and thrusts the audience into Anthony’s psyche as his mental faculties begin to abandon him, is, in fact, a pretext for an epistemological essay in a cinematic-theatrical language of ultimate disorientation. From a literary perspective employing a disability critique, this is an example of what Mitchell and Snyder (2001) termed narrative prosthesis – how narrative functions as a type of prosthetic response to the structure of disability that it inaugurates, propounding the premise of something dysfunctional, needing fixing, some flaw in the natural order, thematized through a disabled character. In *The Father*, the “clinical features of dementia – in some far-along stage (Alzheimer’s presumably) – are accurate and simulate the feeling of descending into a strange, spatially disoriented world” (Wijdicks 2021: 987). In other words, director Zeller is after emulating a typified experience rather than understanding a person in a particular distressful situation. Not the horror of Alzheimer’s is at the center of the experience he tries to recreate, but the threat of losing one’s bearings, that is, losing a home, dear ones, identity, security,

etc. Dementia is, hence, staged as the perfect example of an immersive experience of loss.

In Zeller's stage play, the name of the man living with dementia was Andre. In Le Guay's adaptation, it was changed to Claude. In his recent film version, Zeller changed the protagonist's name again, this time to Anthony, another strategy for blurring the thin dividing line between fact and fiction. At the same time, this might serve another purpose, in the opposite direction, that of keeping the viewer at a safe distance, as it illustrates the principle of viewer duality. On the one hand, Hopkins' acumen, added to his actual age, makes for a powerful "under the skin" affinity with the character he portrays. But Anthony Hopkins is simultaneously and inseparably the actor and the 83-year-old person who approaches, as he himself made clear in an interview, the stage of threatened lucidity. Anthony the actor and Anthony the character are, thus, de-differentiated: Is it just Anthony the character or also Hopkins, the 83-year-old whose awaited failing consciousness we are witnessing?

However, the audience, put in the "unique position" experiencing losing all bearing, has one bearing that it cannot lose: the star status and cinematic persona of Sir Anthony Hopkins. The movie industry and the media have developed the "star system" whose celebrity discourse greatly influences the film's reception (deCordova 2001). Anthony, the character, is in danger of losing his identity, but Anthony, the stage and screen hero, is in no such danger. He will never be, in the consciousness of the film audience, the anonymous everyman with whom we are intended as viewers to immerse ourselves. Hopkins' theatrical performance (Mirodan 2018) adds to this effect, keeping the audience continuously aware of the distance between the man and the character. As a film icon, Anthony Hopkins is removed from the ordinary. Personhood and persona are mutually exclusive, on as well as off the stage. In other words, there is an inherent contradiction in recruiting an extraordinary theatrical persona to portray an ordinary person in a humanly excruciating position.

Zeller says he had the face of Anthony Hopkins in his mind when considering a cinematic adaptation of his play (Beasley 2021). Which "face" of Hopkins did he have in mind? The Shakespearean thespian playing *King Lear* (Eyre & Shakespeare 2018) or Hannibal Lecter of *The Silence of the Lambs* (Demme et al. 1991)? The emotionally inhibited head butler of *The Remains of the Day* (Ivory et al. 1993)? (The Editors of Encyclopaedia

Britannica 2022). Hopkins' film persona integrates all three, perhaps others too, and although his cinematic output certainly exceeds these performances, it is remarkable that these three roles share aspects of pathology. The inevitable awareness of the audience of Hopkins' extraordinary talent in portraying characters with pathology may have an impact on them, making the case for dementia qua pathology and a manifestation of "otherness."

Another issue that emerges from Zeller's brief interview concerns the conversion of the play into film: "I thought that the cinema, thanks to its language, could be more effective than the stage" (Beasley 2021). Zeller does not specify in what ways the screen is more effective than the stage. Is it reproducing a state of dementia? Drawing the viewer into the subjective reality that presumably constitutes the (un)consciousness of a person with dementia? In any case, Zeller is interested in the emotional effect, an exercise in an experiential approximation of a state of "total loss" uncritically and superficially believed to be definitive of dementia. The intentional emphasis on immediate emotional impacts becomes the only venue for approaching a state of cognitive impairment in general and dementia in particular. The film theatrically dramatizes the agony, thus lending support to widespread cultural perception. The more brilliant the performance, the more powerful the impact, overshadowing a more balanced appraisal of dementia.

While going a long way to creating a state of mind of perceptual disorientation and uncertainty for the viewers, *The Father* unintentionally highlights the opposite of what seems to be a state of "obstinate questioning," that is, the ontological certainty concerning the nature of dementia, its manifestations, and the direction of its trajectory. This is where *Floride* makes a difference, unsettling positivistic certainties as to the realities of dementia as a culturally constructed predicament.

Beyond Personhood: Dementia and Personality in *Floride*

The late Jean Rochefort, 85 years old at the time of *Floride's* release, is not well-known to movie-goers outside of France. His portrayal of the leading role of an older man with dementia is undoubtedly masterful, exemplary in its use of ambivalence and understatement, qualities less immediately appealing to mainstream audiences than the grand scale, dramatically

inflected performance style of Anthony Hopkins. An alternately delighted and bewildered Claude, as embodied by Rochefort, “the amused self-acceptance of an ageing male’s misshapen body ...would appear to offer a suitable tribute to Eros and at least a temporary refuge from Thanatos.” (Dine 2022: 66 [referring to Downing 2004: 89-96]).

In the first scenes, Le Guay approaches the exposure of dementia with deliberate hesitation. At first, we think Claude is doing okay because it is made clear that he is pretending to be suffering from some form of dementia just to torment the people around him.

Hopkins’ Anthony is busy pretending to be his former, pre-dementia, own man. This pretense is certainly and unambiguously an act, a calculated, belabored exaggeration, making it a sad parody. With Rochefort, pretense is less a confusion than a strategy. He does not act the pretense but embodies it as a genuine part of his character and a manifestation of his elusive charm, even as this charm progressively evolves into social embarrassment. The veteran actor’s comic talent “allows the ageing star to extract laughter from us that is all the stronger because we are well aware that there are things we should not laugh” (Sotinel 2015 [translated into English by Dine 2022: 72])

In contrast, Hopkins, in *The Father*, artfully affects his charm, which thus becomes another devastating demonstration of his anguish. He takes great pains to redeem from the oblivion of dementia the charmer he once was and no longer is, a vanity sought in vain. This achievement depends on his artful performance, an effortless performance of an effortful charm, a failing attempt at self-preservation. On the other hand, Rochefort’s charm has an unaffected, immediate spontaneity as a part of his character he brings into the new and challenging situation. This charm is re-integrated into his coping style, still easy, but now often a subterfuge in the new game of “getting away with it,” keeping the threat of forgetfulness at bay.

Among the “objectionable” things Claude does, while Anthony significantly does not, are acts of exposure in public, “bad,” and explicit libidinous behaviors. In one scene, he urinates in front of a shocked female stranger. These visceral exposures, embarrassingly comical as they may be, have no place in *The Father*, where, as in most mainstream products sparing “indecent exposures,” more “decent” displays of impairments are preferred. Demonstrating some of the prevailing cultural views of

dementia, Anthony's dementia is depicted first and foremost through the blow to one's individual independence. First, there is a blow to intellectual independence; Anthony's paradoxical articulation, "I am intelligent," expresses wonderment and deep anxiety at the cognitive loss he is experiencing, as his human significance is synonymous with his brain. His whole being takes place in the space between his own mind (the mind he owns) and the fear of losing his mind, a space that is progressively and catastrophically reduced in the course of the play\film.

Second, there is a blow to individual independence in the sense of infantilization. Anthony is reduced to a needy, completely dependent infant, reflecting the ideological implications of understanding "old age" in general, and people living with dementia in particular. This is viewed through the lens of dependency and need that does not reflect an ethics of care (Kittay, 2011, 2012, 2019, see below), but rather a discourse of social control, liminality, and disengagement in which older people are relegated to the category of a "second childhood" dependent on others (Covey 1993). A parallel theoretical conception is found in Turner (1987), who discusses childhood and old age as homologous in terms of social liminality and disengagement, or what he calls a lack of reciprocity. The derogatory view of "the elderly" as childish and dependent and the "elderspeak" (equivalent to baby-talk) sometimes used to address older adults are an indication of a discourse of infantilization:

Through this culturally constructed model of dependency, many of those in old age and others who are infantilized—the chronically sick or disabled, for example—may be made to take a conceptual position alongside children on the margins of society (Hockey & James 1993: 13).

Claude, however, continues to maintain a vital dialogue with the world around him, absorbing its scenery and is not indifferent to sensual pleasures even as his reasoning is affected by dementia. The added, open-air scenes are more than locations; they are a statement of connectedness, sentience, and involvement. He still absorbs natural beauty and keeps company with the world and its inhabitants, even when he cannot name them or when social intelligence and social skills fail him.

Floride resonates with Basting's (2009) typology of cultural representations of dementia, belonging to the "not so tragic" category, as opposed to

the “tragic,” here exemplified by *The Father* (the film, even more than the original play), a critical position accurately and persuasively captured by VandenBosch (2021: 1172) in his review:

The Father is a brilliantly accomplished film – from its visual composition to its masterful acting. What I want to explore here is the danger that lies in the film’s unquestioning acceptance of the tragedy narrative that is already deeply embedded in our societal perception of dementia. This prevailing perception is fixated on the losses that dementia can bring, and it ignores the remaining abilities within persons who are experiencing the symptoms of dementia...

VandenBosch (2021) coaxes viewers of *The Father* to consider a different way of presenting the story of dementia in the family, one that will avoid foregrounding the horror and will resolve unrelenting anxiety in some way. It could have been a worthwhile corrective, yet stepping back and taking a broader perspective are precisely what the immersive nature of the spectator’s experience effectively disables. However, an altered, anxiety-mitigating, if unorthodox, perspective is exactly what we get with *Floride*, and it is definitely worth considering.

In *The Father*, Anthony is, in the end, reduced to a needy, completely dependent infant. As to the question posed by Wearing, “...but does this film’s stress on Anthony’s complex ongoing humanity and vulnerability, briefly experienced, in however mediated a form, by the audience, complicate the negativity of the representation?” Her answer is that *The Father* refuses such a compensatory schema (Wearing 2023: 109).

Floride avails another ending. When Claude’s fantastic invention crumbles and palm-covered Miami is transformed into a care center, his response is anything but devastation. It is as if he had known all along (much as the viewer had been suspecting all along) that the whole trip was a fantasy, and there is a sense of acquiescence, a “now I’m ready” admission, a quiet landing as if the mission had been fulfilled. Where *The Father* ends in shattered, excruciating misery, *Floride* ends with a wistful realization of a sad, but necessary, transition. Ironically, it is Claude who, in an extremely poignant scene where the two are drinking the wine he had refused to drink for years, offers consolations, a reconciliation, and hope to his daughter: “one should not be cross with wine or with people either ... it is a waste of time ... You are good, Carole. Are we going to see each other?” Neither is playing down the heavy demands of the

new situation, yet the fact that the two figures, the older man living with dementia and his principal caregiver, are together in the same frame offers a different prospect and, with it, a different perspective than the one offered in *The Father*. Once Anthony is moved to a place of care, Anne, his daughter, disappears from the scene, raising in the viewer the understanding that she will not come back because there is nothing left to come back to and that, at this stage, there is no care that she can provide. By contrast, Carole stays in the picture. Having left the institute after their conversation, the closing shot is a close-up of her face, looking in the direction of her father's new place, expressing not one feeling, but a mixture of sadness, gratitude, and hope, definitely not guilt and anguish. Most important, her gaze is looking forward rather than backward. She will be back, very likely, perhaps for another story her father will make up. Thus, *Floride* succeeds in "captur[ing] the frustration on both sides, but also the love that, in the end, triumphs over even their most bitter squabbling" (Kelly 2015). This can be seen as demonstrating an alternative view of dependence, one that has been propounded by Kittay (2011, 2012, 2019), who, in a series of publications, developed an ethics of care emphasizing relationality that is based on the personhood and dignity of people - including those with cognitive impairments. Such care foregrounds the affective connection between people as prior to a calculative reason that binds self-interested persons (Interview with Eva Kittay, Care Ethics Research Consortium 2021). In this view, people without disabilities are only "temporarily abled." Dependency relationships between "unequals" are often inevitable, and therefore, assistance should not be seen as a limitation, but as a resource.

Floride as a Metaphor for Coping with Memory Loss Through Imaginative Fiction

More than a physical location, Florida represents a state of mind for Claude (DeBruge 2015). His other daughter, Alice, left France for the Sunshine State some 15 years earlier. Claude's imagination is very alive, even as his cognitive capacities are reduced in dealing with reality. The scenes in "the plane to Miami" as well as the scene in "Miami" have a double function. The first is to deliberately confuse the audience, thus putting it in the position of the person with dementia, a narrative vehicle also

deployed in *The Father* as a horror-magnifying device through the clever use of camera work. In *Floride*, there is another, arguably more important significance, and that is the validation of personhood through storytelling. The scenes on the plane to Florida, as well as the sequence in Miami, are at once figments of Claude's imagination and an act of make-believe, intended not to be taken too seriously. *Floride* belongs not merely to the not-so-tragic cultural representations of dementia but also to the "not so serious" category. It constantly and effortlessly moves between the factual reality of living with dementia and the unreal world of inventive imagination, each equally valid, thus homogenizing two seemingly conflicting approaches into a complex, not easily separated whole.

Rocheport's charm has an unaffected, immediate spontaneity, which he brings into the new and challenging situation he finds himself in. When he is shown the old age home, his new "home," he takes a motor wheelchair left in the corridor and drives it happily around the place, showing activity, entrepreneurship, and coping. Claude portrays the uninhibited audacity of an "enfant terrible," perhaps the alternative to age-coerced infantilization. The trope of the airplane flight is significant: going to Florida is a flight of the imagination on wings of fantasy, blurring the divide between the real and the imaginative the way children do. Claude's behavior provides an extreme contrast to dependence while also reflecting it. He is challenging to manage yet forgivable. Where *The Father* capitalizes on loss and a tragic fall, *Floride* introduces an alternative mixed bag of human responses to dementia other than fright (and hopeless fight), literally and symbolically encumbered in flight. These creative efforts to retain mental agility and memories enable a person living with dementia to "pass" in a public space, make adaptations in the home, and change their use of language and communication. Indeed, "People with dementia continue to learn new information, incorporate data, and use problem-solving skills to adapt to their changing perceptions" (Power 2014: 20). Such an approach not only explores creativity as a set of relational and negotiated practices that does not focus solely on positive benefits but also incorporates areas where tensions and challenges can emerge.

Floride oscillates between recognizing dementia as a psycho-biological disruption and a parallel, complementary acknowledgment of the vital involvement of the person with dementia in the world around him. Even more, Claude seems to be rising to the occasion, compensating, as it were,

for mental loss with other mental abilities, namely, unsuppressed imagination and uninhibited audacity of some kind of an “enfant terrible.” Baronnet (2021) refers to the difference between the two movies: “... the plot evolves very differently from *The Father*, *Floride* taking the liberty, as its title suggests, to imagine a whole part of the plot around a trip to Florida.”

Whether the trip to Florida is part of the diegesis or a figment of the protagonist’s imagination, a complete fabrication remains suggestively suspended until the very end. Curiously and highly relevantly, it is both. As a narrative device, scenes from the plane and from Miami appear intermittently throughout the film, tying, as it were, the scenes in Annecy. The story thus turns into a parallel narrative. As Claude’s memory and adaptive capacity regress, the trip to Miami progresses. These parallel narratives come together when Claude arrives at the house of his other daughter, Alice, and is told by Alice’s former husband that she had been killed in an accident years before (information of which the audience is aware from the parallel narrative). At that moment, Alice’s house becomes, much like the spatial delusions in *The Father*, a nursing home, the place dreaded so much it had to be denied through a fictitious story. Florida:

becomes this mythical place where you are protected, where nothing can reach you anymore. It is the place of appeasement, where everything that does violence to you in life stops hurting you. Basically, Florida is a bit like a movie theatre, a screen-box where you can dream, where those you love are forever with you (Baronnet 2021).

The fantastic story of the invented trip to Florida is delivered with a comic sub-stratum, where the twinkle is shared by the storyteller himself. While not completely unaware of his deeply troubling condition, he metamorphoses it through an inventive, consoling imagination. The use of flashbacks is a common practice in cultural depictions of declining abilities to comprehend the world and conduct self-care. Flashbacks are commonly used to dramatize loss and decline. A particularly relevant example is the South Korean thriller film *Memoir of a Murderer* (Won et al. 2017), whose narrative replicates the memory deterioration of a person living with dementia using the iconography of flashbacks, circularity, repetition of events, white and black screens, and abrupt cuts to parallel symptoms of the disease (Medina 2022). A few minor flashback scenes in *Floride* notwithstanding, Zeller and Hampton avoid them deliberately,

using more sophisticated means of time and place transitions. Both go for the very moment for which a flashback would have been a digression. The only time that matters for the perfect recreation of the experience of dementia is, for them, the abject disgrace of the moment.

Conclusion

Playfulness is the balancing act offered by *Floride* against the gravity of dementia. In an interview, Zeller maintained that director Phillip Le Guay changed his play beyond recognition (Beasley 2021). The fact, however, is that *Floride* retains the substance of the play it is based on, in terms of narrative, thematic materials, major characters, and dramatic conflicts, making it immediately recognizable, but with an open interpretation in mood and tone.

Floride avoids the trap of a sentimental eulogy for a lost self, introducing a man who is obviously not well but very much alive. The ubiquitous emotional response of relatives, often replicated by people with dementia themselves, that of longing becomes somewhat irrelevant, if not straight out degrading when identity is not severed but prolonged, even when altered, which is the case with Claude. Le Guay and his cast, Rochefort and Kiberlain as the leading characters, portray and treat the protagonist/person with dementia as a complex social being and, above all, contribute to a perception of dementia as a valid, even if demanding, way of being in the world, validating imagination, even when unruly and maladaptive, and a genuine sense of respect for what it means to be a person with dementia in all its various manifestations, keeping an overall sense of doubt in the face of uncertainties. This perception of dementia resonates with Arno Geiger's (2017) attempt to portray dementia in the memoir *The Old King in His Exile*. Geiger documents his father's progress into Alzheimer's disease by "foregrounding his unchanged personhood, gendered self, and embodied, relational subjectivity" (Scharge-Früh 2022: 146).

The humanistic message of *Floride* echoes critical re-interpretations of late style and creativity in artists with dementia (Marcus et al. 2009; Wright 2022). Picasso's "problematic" last works were initially dismissed as senile scrawls before being celebrated as bold experiments (Brown 2018). Dementia as a disease category is incredibly idiosyncratic in manifestation and rarely runs a smooth course of manageable

decline (Kitwood 1998). Capacities can wax and wane; sudden losses are frequently observed while varying degrees of “rementia” (temporary regaining of abilities) are also quite common. A powerful illustration of such a “rementia” text that reverses typical biomedical and socio-cultural narratives related to Alzheimer’s disease is Walrath’s (2016) graphic memoir, *Aliceheimer’s*, whose underlying notion is that people living with dementia are individuals who have entered into “wonderlands of their own creation” (Venkatesan & Kasthuri 2018: 80). Rementia is a process requiring a cautiously negotiated “structuring and de-structuring” of the self and its changing relation to the world (Golander & Raz 1996: 271). Claude’s inventive playfulness and its validation by those around him resonates with the recent growing interest in person-centered, “living well” approaches to dementia, often taking the form of efforts to engage people living with dementia in a range of creative, socially inclusive activities that help to affirm personhood and redress the biomedical focus on loss and deficit. However, by emphasizing more traditional forms of creativity “interventions,” more personal and idiosyncratic forms of creativity that emerge in everyday life have been overlooked, specifically with regard to how such creativity is used by people living with dementia and by their carers and family members as a way of negotiating changes in their everyday lives (Bellass et al. 2019).

In *Floride*, in place of flashbacks, we have the opposite, flash-forward: the imaginary trip to Miami is a projection of the inner screen of Claude’s mind onto the screen of the film, symbolically making the future a tangible psychological presence. This is provocatively implicit in one of the last shots in the film, where he looks out through the window of his new room and sees not the yard of an asylum but the tropical flora of Florida: “Dear me, they too have palm trees. I wouldn’t have believed ... [pause] ... Florida is indeed beautiful!”

Corresponding Author

Esther-Lee Marcus, Geriatric Division, Herzog Medical Center, POB 3900, Jerusalem 9103702, Israel. Email: estherlee@herzoghospital.org

References

- Addison, H. (2003). *Hollywood and the Rise of Physical Culture (Studies in American Popular History and Culture)*. New York: Routledge.
- Baronnet, B. (2021, March 18). *Floride sur France 3: connaissez-vous le lien avec The Father, nommé 6 fois aux Oscars?* [Florida on France 3: Do You Know the Link with The Father, Nominated 6 Times at the Oscars?]. CultActu. Available on <https://www.cultactu.fr/floride-sur-france-3-connaissiez-vous-le-lien-avec-the-father-nomme-6-fois-aux-oscars> (Accessed: November 9, 2023).
- Basting, A. D. (2009). *Forget Memory: Creating Better Lives for People with dementia*. Baltimore, MD: Johns Hopkins University Press.
- Beasley, T. (2021, June 11). 'The Father': Florian Zeller Made the Film in English for Anthony Hopkins (exclusive). Yahoo! Movies. Available on https://uk.movies.yahoo.com/father-florian-zeller-anthony-hopkins-121006349.html?guccounter=1&guce_referrer=aHR0cHM-6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig=AQAAABm-DXVguVj4IPtdEmfNHJw59gSIE9xv7XsqHjM5RMpKznCyTmP-CknS0Hjdu99Nf_xPW5XenUo12f7AMAji75YT5vDptAR9u4bED0FA-TMgu_b6gLLiCxdp-j40HPpJd-MPJS4PcyStkhCYeHE5OrSxN1amPc_t3YLX_HjVS98Ndcs (Accessed: November 9, 2023)
- Bellass, S., Balmer, A., May, V., Keady, J., Buse, C., Capstick, A., Burke, L., Bartlett, R. & Hodgson, J. (2019). Broadening the debate on creativity and dementia: A critical approach. *Dementia* 18(7-8): 2799-2820. doi: 10.1177/1471301218760906
- Boukhrief, N. (Director/Writer) & Moreau, F. (Writer). (2008). *Cortex* [Film]. Les Films du Worso; France 3 Cinéma, Wild Bunch [French, English Subtitles].
- Brown, M. (2018). Late style and its discontents: Essays in art, literature, and music. *Comparative Literature Studies* 55(2): 423-427. doi: 10.5325/complitstudies.55.2.0423
- Capp, R. (2020). Head full of honey: Finding the sweet spot on dementia awareness. *The Gerontologist* 60(2): 359-361. doi: 10.1093/geront/gnaa002
- Capp, R. (2021). *The Father*: Big lessons from "little daddy." *The Gerontologist* 61(7): 1170-1171. doi: 10.1093/geront/gnab098

- Capstick, A., Chatwin, J. & Ludwin, K. (2015). Challenging representations of dementia in contemporary Western fiction film: From epistemic injustice to social participation. In A. Swinnen & M. Schweda (eds.), *Popularizing Dementia: Public Expressions and Representations of Forgetfulness Aging Studies (Series)* Vol. VI (pp. 229–251). Bielefeld: Transcript Press.
- Care Ethics Research Consortium. (2021). *Interview with Eva Feder Kittay*. Available on <https://care-ethics.com/tag/philosophy/> (Accessed: November 9, 2023)
- Chang-dong, L. (Director/Writer). (2010). *Poetry* [Film]. UniKorea Pictures; Pine House Film; Diaphana Films [Korean, English Subtitles].
- Chivers, S. (2011). *The Silvering Screen: Old Age and Disability in Cinema*. Toronto: University of Toronto Press.
- Cohen-Shalev, A. & Marcus, E. L. (2012). An insider's view of Alzheimer: Cinematic portrayals of the struggle for personhood. *International Journal of Ageing and Later Life* 7(2): 73–96. doi: 10.3384/ijal.1652-8670.1272a4
- Covey, H. C. (1993). A return to infancy: Old age and the second childhood in history. *The International Journal of Aging and Human Development* 36(2), 81–90. doi: 10.2190/3FNY-20EM-7L4Y-5FGM
- DeBruge, P. (2015). *Locarno Film Review: 'Floride'. Jean Rochefort's Most Rewarding Role Since 1990's 'The Hairdresser's Husband' Gives the French Thesp a Welcome Late-Career Chance to Shine*. Variety. <https://variety.com/2015/film/reviews/floride-film-review-1201566391/> (Accessed: November 9, 2023).
- DeCordova, R. (2001). *Picture Personalities: The Emergence of the Star System in America*. Champaign, IL: University of Illinois Press.
- Demme, J. (Director), Harris, T. (Writer) & Tally, T. (Writer). (1991). *Silence of the Lambs* [Film]. Strong Heart/Demme Production; Orion Pictures.
- Dine, P. (2022). Jean Rochefort as ageing star: Masculinity and masquerade. In T. Tracy & M. Schrage-Früh (eds.), *Ageing Masculinities in Contemporary European and Anglophone Cinema* (pp. 60–74). New York: Routledge.
- Downing, L. (2004). *Patrice Leconte*. New York: Manchester University Press. doi: 10.7765/9781526141712
- Ewen, S. (1976). *Captains of Consciousness: Advertising and the Social Roots of the Consumer Culture*. New York: McGraw-Hill.

- Eyre, R. (Writer/Director) & Shakespeare, W. (Writer). (2018). *King Lear* [Film]. Playground Entertainment; Sonia Friedman Productions; British Broadcasting Corporation (BBC).
- Featherstone, M. & Hepworth, M. (1991). The mask of ageing and the postmodern life course. In M. Featherstone, M. Hepworth & B. S. Turner (eds.), *The Body: Social Process and Cultural Theory* (pp 371–389). London: Sage Publications. Available on <https://sk.sagepub.com/books/the-body/n15.xml#:~:text=DOI%3A,org/10.4135/9781446280546> (Accessed: November 10, 2023)
- Gilbey, R. (2021, March 4). *Florian Zeller on The Father: 'Anthony Hopkins Took me in the Arms. We Knew the Miracle had Happened'*. The Guardian. Available on <https://www.theguardian.com/film/2021/mar/04/florian-zeller-father-anthony-hopkins-miracle-olivia-colman> (Accessed: November 10, 2023).
- Golander, H. & Raz, A. E. (1996). The mask of dementia: Images of 'demented residents' in a nursing ward. *Ageing and Society* 16(3): 269–285. <https://doi.org/10.1017/S0144686X00003421>
- Geiger, A. (2017). *The Old King in His Exile* (S. Tobler, Trans.) New York: Restless Books (Original work published 2011).
- Heeschen, V. (2001). The narration "instinct": Signalling behaviour, communication, and the selective value of storytelling. In J. Trabant & S. Ward (eds.), *New Essays on the Origin of Language. Trends in Linguistics Studies and Monographs* (vol. 133, pp. 179–196). Berlin, New York: de Gruyter. doi: 10.1515/9783110849080
- Hockey, J. & James, A. (1993). *Growing Up and Growing Old: Ageing and Dependency in the Life Course*. London: Sage.
- Ivory, J. (Director), Ishiguro, K. (Writer) & Prawer Jhabvala, R. (Writer). (1993). *The Remains of the Day* [Film]. Columbia Pictures; Merchant Ivory Productions.
- Kelly, B. (2015). *Review: French Film Floride Captures Challenge of a Stubborn Parent Losing His Mind. Floride is a Powerful Moving Drama About an 81-Year-old Man Living in Annecy Who Is Causing No Small Amount of Trouble for the People Around Him*. Montreal Gazette. Available on <https://montrealgazette.com/entertainment/movies/review-french-film-floride-captures-challenge-of-a-stubborn-parent-losing-his-mind> (Accessed: November 9, 2023)

- Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris* 24(1): 49–58. doi: 10.1111/j.1467-9337.2010.00473.x
- Kittay, E. F. (2012). Getting from here to there: Claiming justice for the severely cognitively disabled. In R. Rhodes, M. Battin & A. Silvers (eds.), *Medicine and Social Justice: Essays on the Distribution of Health Care* (2nd ed., pp. 313–324). New York: Oxford University Press. doi: 10.1093/acprof:osobl/9780199744206.003.0026
- Kittay, E. F. (2019). *Learning from My Daughter: The Value and Care of Disabled Minds*. New York: Oxford University Press.
- Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.
- Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *The Journal of Clinical Ethics* 9(1), 23–34. doi: 10.1086/JCE199809103
- Langford, B. (2005). *Film Genre: Hollywood and Beyond*. Edinburgh: Edinburgh University Press.
- Le Guay, P. (Director/Writer), Tonnerre, J. (Writer) & Zeller, F. (Writer). (2015). *Floride* [Film]. Gaumont; F Comme Film; Ciné@ [French, English Subtitles].
- Low, L.-F. & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics* 20(1): 477. <https://doi.org/10.1186/s12877-020-01754-x>
- Marcus, E. L., Kaufman, Y. & Cohen-Shalev, A. (2009). Creative work of painters with Alzheimer's disease. *Harefuah* 148(8): 548–553.
- Medina, R. (2018). *Cinematic Representations of Alzheimer's Disease*. London: Palgrave Macmillan.
- Medina, R. (2022). Writing the past to fight Alzheimer's disease: Masculinity, temporality, and agency in *Memoir of a Murderer*. In H. Hartung, R. Kunow & M. Sweney (eds.), *Ageing Masculinities, Alzheimer's and Dementia Narratives* (Bloomsbury studies in the humanities, ageing and later life) (pp.125–141). London: Bloomsbury. Available on <https://www.bloomsburycollections.com/monograph-detail?docid=b-9781350230637&tocid=b-9781350230637-chapter7#:~:text=DOI%3A%2010.5040/9781350230637.ch%2D007> (Accessed: November 10, 2023)
- Mirodan, V. (2018). *The Actor and the Character: Explorations in the Psychology of Transformative Acting*. London: Routledge.

- Mitchell, D. T. & Snyder, S. L. (2001). *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor, MI: University of Michigan Press.
- Novaro, M. (Director/Writer). (2010). *The Good Herbs* [Film]. Axolote Cine; Fondo para la Producción; Cinematográfica de Calidad (FORPRO-CINE); Institute Mexicano De Cinematografía (IMCINE) [Spanish, English Subtitles].
- Power, G. A. (2014). *Dementia Beyond Disease: Enhancing Well-being*. Baltimore MD: Health Professions Press.
- Rai, M. & Banerjee, D. (2022). "The Father": As real as it gets to living with dementia. *Indian Journal of Psychiatry* 64(2): 213–215. doi: 10.4103%2FIndianjpsychiatry.indianjpsychiatry_608_21
- Rave, Y. (2021, October 28). Ha'av: Seret eima me'nei haziknah ve'kol mah shekashur bah. [The Father: A thriller movie about aging and all that is associated with it.] Calcalist. Available on <https://www.calcalist.co.il/style/article/skpqldif> (Accessed: November 9, 2023)
- Sabat, S. R. & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias* 14(1): 11–19. doi: 10.1177/153331759901400108
- Sawicka, K. M., Patel, N., Chan, D. & Tyndel, F. (2022). The father: A neurology film club review. *Practical Neurology* 22(2): 171. doi: 10.1136/practneurol-2021-003258
- Scharge-Früh, M. (2022). Stories of exile and home: Dementia and masculinity in Arno Geiger's *Der Alte König in seinem Exile* and Ian Maleney's *Minor Monuments*. In H. Hartung, R. Kunow & M. Sweney (eds.), *Ageing Masculinities, Alzheimer's and Dementia Narratives* (Bloomsbury studies in the humanities, ageing and later life) (pp.145–161). London: Bloomsbury. doi: 10.5040/9781350230637.ch-008
- Sotinel, T. (2015). *Floride: voyage avec un esprit qui se perd. Au côté de Sandrine Kiberlain, Jean Rochefort bouleverse dans le rôle d'un homme frappé de démence senile* ["Florida": Traveling with a Lost Mind. Alongside Sandrine Kiberlain, Jean Rochefort Is Overwhelming in the Role of a Man Suffering from Senile Dementia]. Le Monde. Available on www.lemonde.fr/cinema/article/2015/08/11/voyage-avec-un-esprit-qui-se-perd_4720267_3476.html (Accessed: November 10, 2023)
- Swinnen, A. (2013). Dementia in Documentary Film: *Mum* by Adelheid Roosen. *The Gerontologist* 53(1): 113–122. doi: 10.1093/geront/gns061

- The Editors of Encyclopaedia Britannica. (2022). *Anthony Hopkins – Welsh actor*. Encyclopaedia Britannica. Available on <https://www.britannica.com/biography/Anthony-Hopkins> (Accessed: November 10, 2023)
- Tseng, C.-I. (2017). Beyond the media boundaries: Analysing how dominant genre devices shape our narrative knowledge. *Discourse Context & Media* 20: 227–238. doi: 10.1016/j.dcm.2017.05.001
- Turner, B.S. (1987). *Medical Power and Social Knowledge*. London: Sage.
- Ustaoglu, Y. (Director/Writer) & Kaygusuz, S. (Writer). (2008). *Pandora's Box* [Film]. Ustaoglu Film Yapim; Silkroad Production; Les Petites Lumieres [Turkish, English Subtitles].
- VandenBosch, J. (2021). Filming the “drama” of dementia. *The Gerontologist* 61(7): 1172–1173. doi: 10.1093/geront/gnab099
- Venkatesan, S. & Kasthuri, R.R. (2018). ‘Magic and laughter’: Graphic medicine, recasting Alzheimer narratives and Dana Walrath’s *Aliceheimer’s: Alzheimer’s through the looking glass*. *Concentric: Literary and Cultural Studies* 44(1): 61–84. doi: 10.6240/concentric.lit.201803.44(1).0004
- Walrath, D. (2016). *Aliceheimer’s: Alzheimer’s Through the Looking Glass*. University Park: Pennsylvania State University Press.
- Walsh, A. (Director), Gibb, A. (Writer) & Healey, E. (Writer). (2019). *Elizabeth Is Missing* [Film]. STV Productions; BBC One.
- Wearing, S. (2023). Frames of dementia, grieving otherwise in *The Father, Relic, and Supernova*. Representing dementia in recent film. In R. Ward & L. J. Sandberg (eds.), *Critical Dementia Studies: An Introduction* (pp. 100–115). New York: Routledge.
- Wijdicks, E. (2021). Lost in plain sight. *The Lancet Neurology* 20(12): 987–988. doi: 10.1016/S1474-4422(21)00144-7
- Won, S. (Director), Hwang, Y. (Writer) & Kim, J. (Writer). (2017). *Memoir of a Murderer*. [Film]. Green Fish Pictures [Korean, English Subtitles].
- Wright, J. (2022). Drawing and memory loss: Mapping and recording the journey through Alzheimer’s disease. *Tracey* 16(1), 1–13. Available on: <https://ojs.lboro.ac.uk/index.php/TRACEY/article/view/353/329> (Accessed: November 10, 2023)
- Zeller, F. (Director/Writer) & Hampton, C. (Writer) (2020). *The Father*. [Film]. Les Films du Cru; Film4; Orange Studio.

Life events and the experience of quality of life among residents of senior housing in Finland

By ANN-LOUISE SIRÉN^{1,2}, MARJAANA SEPPÄNEN¹ & MIKAELA B. VON BONSDORFF^{2,3}

Abstract

A more holistic view is needed regarding the impact of life events on the quality of life of older adults. We explored how senior housing residents perceive the influence of life events on their current quality of life, from a life course perspective. Semi-structured interviews were conducted with 33 residents aged 68 to 97 years from three senior houses. The thematic analysis suggested that events related to social relationships and human agency may influence quality of life in old age. Experiences that contribute to personal development, feeling safe, social connectedness, and a strong sense of human agency were perceived to add quality to life. Events that cause anxiety, reduces one's sense of autonomy, and involve loss of social closeness were perceived to detract from quality of life. Life events can also sometimes evoke

¹Ann-Louise Sirén & Marjaana Seppänen, Faculty of Social Sciences, University of Helsinki, Finland.

²Ann-Louise Sirén & Mikaela B. von Bonsdorff, Folkhälsan Research Center, Helsinki, Finland

³Mikaela B. von Bonsdorff, Gerontology Research Center and Faculty of Sport and Health Sciences, University of Jyväskylä, Finland

conflicting feelings. The study implies that the influence of life events depends on whether human needs are met.

Keywords: independent living, life course perspective, life events, personal autonomy, quality of life.

Introduction

In the light of population ageing, there has been an increased emphasis on investigating factors that may have an impact on older adults' quality of life. Research conducted over the past two decades has found vital links between quality of life and life events (Enwo et al. 2021; Gabriel & Bowling 2004; Ventegodt et al. 2006; Yilmaz & Tekin 2018), that is, significant experiences that may produce considerable and long-term effects either on an individual level or for a larger group of people (Hutchison 2019). The research to date has generally focussed on the impact of life events (Hutchison 2019) that have a disadvantageous influence on older adults' quality of life. Less attention has subsequently been paid to life events that may increase quality of life in old age. It is therefore important to have a more holistic understanding of the influence of life events in the shaping quality of life of older adults. Such events may have various effects depending, for example, on the individual's personal situation at the time of the experience (Cleland et al. 2016a; Swain et al. 2020), including whether the person has social resources at hand (Pocnet et al. 2016), such as a strong sense of closeness in relationships (Wiggins et al. 2004), financial resources (Swain et al. 2020), the experiences that precede the event, and whether the individual has a sense of autonomy (Shrira 2012) and control over the event (Zautra & Reich 1981). Many life events may subsequently be difficult to categorise definitively as either desirable or undesirable (Cleland et al. 2016b). This study therefore aims to contribute to existing literature by taking a step towards understanding the impact of life events on quality of life as a whole.

Quality of Life

The concept of quality of life is widely used in research. In social sciences, such as gerontology, there is a consensus that quality of life is a

multidimensional concept (e.g. Van Leeuwen et al. 2019; Walker & Lowenstein 2009) comprising social, environmental, psychological and physical values (Theofilou 2013). Quality of life has both objective micro-societal and socio-demographic components (Gabriel & Bowling 2004) and subjective micro-individual components (Walker & Lowenstein 2009). The former includes for example the level of income, education and housing (Walker & Lowenstein 2009), and the latter includes individuals' own interpretation of this reality (Xavier et al. 2003).

According to Fernández-Ballesteros (2011), the definitions of quality of life based on lay views are similar to those proposed by experts. Therefore, older adults' own interpretations of what is important for quality of life need to be included in the definition of the concept (Gabriel & Bowling 2004; Walker & Lowenstein 2009). A systematic review by Van Leeuwen et al. (2019), which included 48 qualitative studies aimed at exploring what quality of life means to older adults, identified nine domains of quality of life and associated sub-themes. The domains included health perceptions, autonomy, role and activity, relationships, attitudes and adaptation, emotional comfort, spirituality, home and neighbourhood, and financial security. Clearly, there are many different areas that are important in old age. One of these is life events.

Life Events and Quality of Life in Old Age

Some studies investigating associations between life events and quality of life have found that older adults who have experienced adverse childhood events, such as bereavement, exposure to violence (Enwo et al. 2021) and physical illness (Shrira 2012), are at risk of decreased quality of life. Yilmaz and Tekin (2018), who conducted a study examining the impact of negative events early in life on the quality of life among individuals aged 50–89 years, found that parental indifference to their child's health, and the number of negative events may be important determinants of quality of life.

Other studies have investigated associations between life events that have occurred near or after retirement and quality of life. Wiggins et al. (2004) had the overall aim of identifying and analysing life course and contextual factors that influence quality of life in older adults aged 65–75 years. Their results showed that recent bereavement and major

illnesses lowered quality of life and indicated that a strong sense of closeness in relationships may counteract the impact of such experiences. Another life event that typically occurs near or after retirement is relocating from conventional housing to more supportive housing, such as senior housing.

Relocating to senior housing is known to be one of the most stressful events in old age (Lotvonen et al. 2018) and has been reported to have an impact on quality of life (Roberts & Adams 2018). Senior housing refers to non-institutional residential accommodation that supports independent living for older adults with varying needs for assistance with activities of daily living (Lahti et al. 2021). Whether a move to senior housing causes positive or negative stress responses depends on many factors, including whether the move affects patterns of social interaction, daily habits, and how preceding life events are perceived in relation to the move (Ewen & Chahal 2013). Preceding life events constitute a common reason for relocating later in life, and the occurrence of stressful experiences prior to the move may exacerbate the stress and require making substantial adjustments following relocation (Ewen & Chahal 2013).

A retrospective study by Ventegodt et al. (2006) sought to discover whether previous major life events had an influence on the present quality of life of older adults aged 55–66 years. They found that many small events had a greater impact on quality of life than fewer but larger events. Similar results were reported in a longitudinal study with the aim of exploring associations between life events reported by adults 50 years or older, and quality of life and functional ability (Enwo et al. 2021). The results showed that experiencing maternal coldness, violence in combat, or being exposed to many adverse life events significantly increased the risk of poor quality of life. A similar conclusion was drawn by Shrira (2012) in another longitudinal study focussing on whether lifetime cumulative adversity had detrimental effects on depressive symptoms and quality of life in older adults in the age range 50 to 96 years. The results indicated that individuals with more life course adversity were at greater risk of continuous high levels of depressive symptoms and lower quality of life.

Thus, multiple life events may occur together (Enwo et al. 2021) and tend to cluster at certain stages of the life course (Plagnol & Scott 2011). Moreover, some life events keep individuals on a particular trajectory

whereas others either send life trajectories off track or bring them back on track; such experiences represent turning points, or lasting major negative or positive changes (Hutchison 2019). Turning points can influence quality of life since individuals shift their priorities in terms of what matters to them after such life events (Plagnol & Scott 2011).

Life Course Theory

Understanding the life patterns described above is at the heart of the life course perspective, as they generate diversity and affect many people's lives at the same time (Hutchison 2019). The life course perspective, or life course theory (Alwin 2012), focusses on the experiences that individuals have in their lives from childhood to later life (Elder 1998), and provides a context for understanding how these experiences provide opportunities, or constitute challenges, for human development (Hutchison 2019). This theory has been profoundly shaped by the work of Glen Elder (Grenier 2012: 30), who in the 1990s identified four central interrelated principles (Elder 1994), or main themes, that characterised the life course perspective (Hutchison 2019). Two additional principles were later identified by Elder (1998) and Michael Shanahan (2000) (Hutchison 2019).

Together, these six principles form the framework for life course researchers (Hutchison 2019). The *historical time and place* principle states that the lives of individuals are embedded in and shaped by the historical times and places they experience (Alwin 2012), such as World War II or the Great Depression (Elder 1998). The principle of *timing of life* states that life events can be timely and synchronous in relation to age norms (Elder 1994), or they can be untimely (Elder 1998). The principle of *linked or interdependent lives* asserts that individuals' lives are embedded in social relationships with relatives and friends (Elder 1994); consequently, planned or unplanned transitions in one's life are preceded by transitions experienced by these "significant others" (Elder & Shanahan 2006: 696). The principle *human agency* states that the opportunity to make life choices enables individuals to choose the paths they wish to follow, depending on the opportunities and constraints of history, culture, and social structure (Elder 1998). The principle of *diversity in life course trajectories* asserts that individuals are simultaneously part of multiple socially constructed identity groups, such as gender, age, social class, ethnicity, ability, and

geographical location (Hutchison 2019). Finally, the principle of *developmental risk and protection* states that life events and transitions that occur at one point in time can set in motion other interrelated experiences at later points in time, which can trigger cumulative advantages or disadvantages (Elder 1998; Hutchison 2019) that shape one's entire life.

One of the main strengths of the life course theory is that it looks at all life stages and transitions to understand life patterns (Elder 1998). The framework can be used to understand how life events influence outcomes of interest (Alwin 2012). Therefore, the theory has the potential to further our understanding of how older people's quality of life is shaped by their experiences of life events in different life stages. Surprisingly, none of the studies examining associations between older adults' quality of life and life events appear to have applied life course theory. Instead, researchers have generally drawn on other models, such as Gilbert's evolutionary biopsychosocial model (Ferreira et al. 2021), cumulative inequality theory (Shrira 2012), and the holistic process theory of healing (Ventegodt et al. 2006).

The Present Study

Existing research on older adults' quality of life in relation to life events is mainly based on quantitative data, and hence a more in-depth understanding of the phenomenon from the perspective of older adults themselves is needed. As Grenier (2012: 31) argues, adopting a life course perspective could allow their subjective experiences to take on greater meaning. Furthermore, what is known about the influence of life events on quality of life in old age derives from studies focussing on life events that are expected to have a negative impact, mainly involving study populations with a mean age under 65 years. There is therefore a need to include older adults who have reached retirement age. Since older adults residing in senior housing are typically 65 years or older (Ewen & Shahal 2013; Lahti et al. 2021; Silva-Smith et al. 2011), and senior housing also aims to improve quality of life (Ismail et al. 2021; Silva-Smith et al. 2011; Tyvimaa 2011), seniors residing in such housing were considered to be an appropriate population for this study. Complementing previous research, this study aims to focus on older adults' own interpretations of the changes they have experienced over their life course that shape quality of life in old age. The question we

wanted to answer was: How do residents in senior housing perceive the influence of the life events they have experienced over the life course on their current quality of life?

Methods

This research is part of the BoAktiv Study, a project comprising two parts. The first part investigates physical functioning, mental functioning, loneliness, and health-related quality of life among senior housing residents, but also seeks to investigate whether the residents' functioning (Lahti et al. 2021) and active ageing differ from community-dwelling older adults (Siltanen et al. 2023). The overall aim of the second part of BoAktiv Study is to gain comprehensive data about the perspectives and characteristics of individuals who reside in senior housing and to use the information to create living environments that support good quality of life. While all three authors of the present study have been involved in designing the second part of BoAktiv Study, the first author has been responsible for collecting the interview data used in that part. The study has been reviewed by the ethical review board in the Humanities and Social and Behavioural Sciences, Helsinki University, Finland. All procedures were conducted in line with the guidelines of the Declaration of Helsinki.

Participants and Procedure

Participants were recruited from three independent living facilities, two small (≤ 49 apartments) and one large (≥ 100 apartments), around the southwestern and southern coastal regions of Finland. Independent living facilities are called senior houses in Finland. People who receive a pension or are 55 years or older are eligible to live in the facilities regardless of their income level. The senior houses were run by Folkhälsan, a non-profit organisation that provides social and health services to Finnish citizens at all stages of life (Folkhälsan 2021). All participants lived independently but light supportive services such as housecleaning were available and included in the monthly service fee. Although all the participants were Finnish, most of them had Swedish as their first language, which is one of the two official languages in Finland and is spoken by about 5% of the population. The inclusion criteria were specified as

follows: age ≥ 65 years, intact memory function, and sufficient Swedish language comprehension and speaking ability. Table 1 shows the characteristics of the participants.

One of the smaller senior houses consisted only of rental apartments, whereas the other two had a combination of condominiums and rental apartments. The living costs for the senior houses varied depending on

Table 1. Characteristics of the participants

	<i>N</i> = 33 (%)
Sex	
Women	22 (67)
Men	11 (33)
Age	
70 years or under	3 (9)
71–80	11 (33)
81 years or over	19 (58)
Marital status	
Married	6 (18)
Divorced	6 (18)
Widowed	16 (49)
Unmarried	5 (15)
Level of education	
Primary or secondary	7 (21)
Tertiary	22 (67)
Postgraduate	4 (12)
Chronic condition	
None	5 (15)
One	13 (39)
Two or more	15 (46)
Number of years in current housing	
0–1 year	8 (24)
2–3 years	17 (52)
4 years or more	8 (24)

location, available services, and type of apartment. In the larger senior house, residents could purchase support services from the skilled nursing facility in the same complex. Daily activities such as aqua aerobics and gymnastics for older adults were also available in the larger senior house. One of the smaller senior houses and the larger senior house had a gym, which residents could use as they wished and which was included in the monthly fee.

The in-house manager of each participating senior house agreed to forward an information letter about the study to all Swedish-speaking residents. The letter explained that as senior housing has become an increasingly common type of housing, it is important to gain comprehensive information on the characteristics of senior housing residents and the factors that may influence their quality of life, such as life events. It was also explained that the information gained from the study could be used in the design and development of senior housing. The letter also included an invitation to receive oral information about the study, to ask questions, and to register as a participant. The first author then visited each of the three senior houses to provide detailed information about the study to residents who attended the meeting and were interested in obtaining more information. She explained that the overall aim of the study was to gain a deeper understanding of what senior housing residents associate with quality of life and which life events made life better or worse – either enhanced or reduced quality of life – across the life course as well as at the present time. The researcher also informed the participants that the study was part of her doctoral research and that she had previously worked on various public health projects, such as promoting healthy ageing and preventing unwanted loneliness among older adults. After receiving information about the study, the majority of those who had attended the information session in each senior house, 32 residents, agreed to participate and signed an informed consent form. The first author informed the residents who attended, as well as the in-house managers, that more participants were welcome, which resulted in one additional participant. None of the 33 participants dropped out. The few residents who attended the meeting but chose not to participate stated that they declined because of age-related conditions, such as severely impaired hearing.

Study Design and Analysis

Since we wanted to ask older adults to describe key events they had experienced in their lives, we decided to conduct in-depth semi-structured interviews that allowed them to talk about quality of life in the context of their overall life (Gabriel & Bowling 2004). An interview protocol was created that included questions regarding quality of life, life events, and the life course. Pilot interviews were conducted by the first author with older adults who provided feedback that was used to improve the interview protocol. Consistent with Xavier et al. (2003), we found that the individuals in the pilot interviews found the term "quality of life" difficult to understand. We therefore decided to rephrase our questions to include only the word "life"; for example, instead of asking participants which life events enhanced or reduced their quality of life, we asked them about events that made life better or worse. This rephrasing was considered to preserve the intelligibility of quality of life as well as the validity of the original intention with regard to the questions (Xavier et al. 2003). To obtain relevant information about life events across the life course that the participants associated with their quality of life, they were asked about life changes or events that had occurred during different life stages. The open-ended question that everyone was asked for each life stage was: "What changes or events do you consider have made your life better or worse?" At the end of each interview, all participants were asked: "Which of the life events that you have talked about today, positive or negative, have most influenced your ability to live a good life at present?"

The first author also conducted all interviews with the participants in the present study. She had met all the participants before the actual interview and talked to them individually. The interviews were conducted in Swedish between September and November 2021 in the residents' apartments or another convenient location within the senior house. One participant had his son present during the interview and another had his wife present. The participants were asked if they were comfortable with the interview being recorded and with the interviewer taking notes during the interview. All interviews were audio recorded, except for one where the

researcher only took notes at the participant's request. The length of the interviews ranged from 45 to 128 minutes (mean duration 84 minutes).

Our collected data were analysed by performing thematic analysis because it offered a systematic technique for identifying, analysing, and interpreting patterns of meanings, namely themes, within the qualitative data (Clarke & Braun 2017). To conduct a reliable thematic analysis, we followed the six-phased iterative and reflective process suggested by Nowell et al. (2017), which included familiarising ourselves with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report. In the current study, thematic analysis was used to gain a broader understanding of how senior housing residents perceive the influence of life events on their current quality of life. As we wanted to apply existing theory and literature together with our raw data to explain the patterns and story behind the data, we decided to employ abductive reasoning in our thematic analysis (Thompson 2022).

All the interviews in the present study were conducted by the first author, who also transcribed them verbatim into MS Word documents during the data collection phase. Each participant was informed that their transcript was available upon request, and one participant asked to have his sent to him. The first author then actively read the transcripts to become familiar with the dataset as a whole and to identify potential codes in the raw data. Similar phrases and words were highlighted in the same colour. The first round of codes was discussed with the other authors. Some of the codes seemed to be irrelevant to our research question. Further rounds of coding were therefore conducted by the first author, a process that resulted in a reduced number of codes. Once all of the authors had reached a consensus on which codes to include in the analysis, we began to group the codes into different categories, or themes. We moved back and forth between the different phases numerous times before we felt that we had captured the essence of what we wanted to explore. Eventually, two main themes emerged that we considered to encapsulate the essence of how our participants related life events to their current quality of life. After some consideration, we added a third main theme with the codes "mixed feelings" and "both positive and negative consequences," which had originally been part of the other main themes. In the development

of the included themes, we considered both the raw data as well as existing literature, and the life course perspective.

Overall, the data in each main theme were intertwined and thus difficult to separate. One of the themes, however, included data that clearly captured different aspects and were accordingly divided into sub-themes (see Table 2 for an overview of the identified codes, sub-themes, and main themes). Finally, all the participants received information about our interpretations and had the opportunity to comment on them.

Findings

In this section, we will present the findings from the three main themes and two sub-themes that reflect how our participants related life events

Table 2. Overview of the identified codes, sub-themes and themes during the analysis process

Codes	Sub-themes	Themes
Have something in common, belonging, new enriching relationships	Feeling socially connected	Experiences providing opportunities to live a life that one values
Make own decisions, freedom, develop skills, cultivate talent, develop interests, achieve goals, preferred lifestyle	Developing as a person	
Beyond one's control, worry, loss of independence, loss of freedom, anxiety, loss of enriching relationships, feeling out of place, insecurity		Disruptive experiences restricting the possibilities to live a life that one values
Mixed feelings, both positive and negative		Experiences providing both opportunities and constraints to live a life that one values

that they had experienced across the life course to their current quality of life.

Experiences Providing Opportunities to Live a Life That One Values

Life events that our participants had found desirable and that had generated additional gains, such as new social connections or being the starting point for other positive life events, were perceived to add quality to life, making their current life better. Such life events allowed them to feel content over time.

Feeling socially connected. When the participants talked about life events that made life better, they often mentioned that these experiences had contributed to social relationships with people that had become very central to their lives. Some of these life events had been the starting point for other interrelated occurrences, such as meeting one's future spouse or getting married. Almost one-third of participants considered that such life events had improved their quality of life, primarily because they had led to other life events that had made life better, such as having children and grandchildren. When asked about the life events that had made their current life better, one participant said:

Meeting my wife was naturally the biggest change... and children and the grandchildren. I hadn't imagined a life with children. And it's been really lovely, not to mention the grandchildren. They're amazing, a great joy [...] (P33).

Many of those who had children similarly reflected that without marriage they would not have their children, who were the central people in their lives.

Several other life events were similarly perceived to add quality to life because they contributed to enriching relationships. Taking up a hobby was such an event for approximately half of the participants. While the hobby remained important because it was fulfilling and provided opportunities to develop skills and to progress, it also provided opportunities to develop satisfying social relationships with people who shared their interest. One participant, who was a member of a choir, illustrated this by saying:

Singing and socialising with others [in the choir] is something that makes life good. Those who sing in the choir have become dear to me over the years and are people I enjoy spending time with (P22).

A hobby could duly foster lasting and enriching relationships with people with whom they had something in common. This was considered an important aspect of several other life events that added quality to life because it built a sense of connectedness and belonging.

It was common for participants to explain that the social relationships they had developed in conjunction with life events continued to enrich their social life. The choice of education or profession were examples of such events. As one participant said:

I have a group of colleagues that I started collaborating and planning joint projects with for mother tongue teachers [...] The companionship was good and is still good and active (P28).

Even if the patterns of social interaction with former colleagues changed and often decreased after retirement, it was important for many of our participants to maintain and nurture friendships with people with whom they had something in common.

Diminished social connections, due to widowhood or a change in health status, had been a reason for relocating to senior housing. Nearly half of the participants said that the move had enriched their social life. For several of the participants, the move had enabled them to maintain social connections or to reconnect, which added quality to their lives. This was illustrated by a participant when he said:

These old friends of mine, like my classmates, are quite important; we all think so. It's pretty fantastic [...] I've met some of my old classmates from the 1930s [here at the senior house]. We started school together and now we live here together (P19).

The opportunity to socialise with fellow residents with whom they had something in common contributed to the feeling that relocating was a happy life event.

Developing as a person. Our participants emphasised how important it was to have the autonomy to make decisions regarding life events that could shape their entire future, and subsequently influence whether they

could live the kind of life they had planned and hoped for. The choice of education and profession were such events. One of the participants said that because he had stood up to his parents, he had been able to become what he wanted:

[...] my parents had wanted me to become an engineer, but I had a will of my own and did well - I became a military officer [...] (P5).

He felt that it was a profession that had suited him perfectly and he had developed people skills that had helped him to communicate and interact with others efficiently. Several of the participants similarly explained that the skills they had acquired thanks to their education or profession allowed them to contribute to the well-being of others. One participant exemplified this by saying:

My [nursing training] has been useful many times, even here at times [in the senior house]. Some [fellow residents] are tired and low, and I make them feel happier [...] It comes naturally to me. I see the need, so I'm pleased and happy (P9).

Having the autonomy to pursue a qualification or profession they had their mind set on could have been the starting point for other life events that enabled them to steer their life in a desirable direction from that point on. Some of the participants had taken purposeful actions to achieve their goals. As one participant stated:

It's like a stepladder... without the first step, I wouldn't have reached the others. So really, let's say it was a decision back in school to plan well for the rest of my life [...] without the first step, I wouldn't have succeeded [...] it was never that I was after money, but one thing led to another (P23).

As this quote illustrates, that first choice had also led to other positive outcomes such as financial security, both during working life and in old age.

Another life event that had often been well-planned was relocating to senior housing. Many of the participants considered that it had been one of the best decisions they had made, partly because the accommodation met their current needs. For example, the move enabled them to continue living independently and to come and go as they pleased, which facilitated an active lifestyle, such as spending a lot of time outdoors or taking

part in cultural activities outside the senior housing sphere. One participant who had an active everyday life said:

I have many illnesses, but I'm keen to try to take part in everything. I take part in senior dancing, and now we're starting choir [practice] again [...], and tomorrow is Oktoberfest, so we have a lot going on (P21).

Staying healthy for as long as possible was a vital goal for many residents, and the relocation facilitated physical activity. As one participant said:

There are so many opportunities here when it comes to what I praise the most, which I didn't have [when I lived] in the countryside, and that's the nice gym [...] So that makes it work for me because I have a will to live. I want to live as long as possible (P22).

The relocation had duly made it easier for some of the participants to pursue an everyday life that was in line with what they valued.

Disruptive Experiences Restricting the Possibilities to Live a Life That One Values

In contrast to the theme presented above, this theme represents life events over which the participants had no control, and which could have led to a decline in quality of life. Such experiences involved either loss of social closeness or connectedness and/or a lack of autonomy.

Six participants said that the disruptive life events that had taken place during World War II had left a mark on them. Several of these respondents were worried about the possibility of being affected by war once again. As one participant put it:

War overshadows everything [...] There are so many troubles and sorrows that come with it [...] I hope that there won't be any more [wars before I die], but all the time you can see powerful military commanders and statesmen who have problems behaving themselves (P19).

More than half of the participants had been sent away as a war child during World War II. For those who had perceived it as a negative life event or

who had experienced adverse life events while away from their family, it was important to make sense of their experiences. However, some of them had never had the opportunity to do so, which made it difficult to heal and get closure because other people, particularly their parents, had been reluctant to talk about it. One of the participants called for redress:

I'm waiting for an official day [devoted to war children] [...] Or at least the opportunity to get therapy, or some sort of compensation (P 7).

Most of the participants who had experienced disruptive events due to the war reported that as adults they had increasingly begun to reflect on and think about the negative effects of their experiences.

Participants felt that certain life events had restricted their freedom to shape their lives in a desirable direction. Being prevented from pursuing the education they wanted was one such event. As one participant commented:

It was actually my aunts who decided my profession [...] Well, I enjoyed my job, but the [low] wages [...] I would rather have done something else [for a living] (P7).

This participant said that she had struggled financially throughout her adult life due to low wages and a low income after retirement.

Retirement could therefore be perceived as financially distressing for some. Several of them had retired too early due to the development of a chronic disease, for example, which had led to a much lower pension than they had anticipated. Untimely retirement was generally perceived as undesirable because most of these participants had wanted to continue working until full retirement age.

Developing a chronic disease or condition could therefore take life in a different direction than expected. Several participants said that their changed circumstances had led to a decline in their psychological well-being. One participant who had been diagnosed with an eye disease stated:

Sometimes I get depressed, and sometimes I feel that everything's so boring [...] I would like to have more energy to do the things I have the chance to do, but the eye disease restricts me. If I didn't have this bad eyesight, I wouldn't be living here [in the senior house], or even be in this country. When I was still working, I used to dream of spending my winters as a retiree [in a warm country] (P12).

Some of those who had developed a chronic disease said that they had become socially withdrawn and therefore seldom took part in social activities, both outside and inside the senior house sphere. These respondents stated that they felt rather isolated and lacked close relationships.

A life event that had also led to life taking an unwanted turn was having a spouse who had unexpectedly fallen seriously ill. These participants said that it was sad to witness their spouse's health deteriorate and no longer be able to do things together. They also reported that the changed circumstances had affected their psychological well-being.

Another type of disruptive life event involving the loss of close relationships was the death of a spouse, relative or close friend. Several of the participants whose spouse had died explained that the grief was always present, despite having an overall fulfilling social life and everyday life. One participant explained:

For the most part, I manage pretty well, but at the weekends, regardless of what I have planned, such as my granddaughter's birthday party next Sunday, I become a bit melancholy. It's only a little over two years since my husband died, and we had been married for 60 years. The loss becomes palpable every now and then. You never quite get over it (P21).

For some, losing someone close to them meant that they no longer had anyone to confide in or do things with. As one participant said:

It's an enormous sense of loss. She [my sister] was the only human being I could talk to about everything, everything. There were no secrets... Now there's no one [I can talk to] (P18).

Several participants who no longer had any close friends alive said that they longed to find someone with whom they had a similar connection. These respondents also expressed feelings of loneliness.

Losing someone close could be a life event that resulted in relocating to senior housing. Even if most of the participants had chosen to relocate of their own free will, some said that the move had not been their choice. Several of them had felt obliged to move because their children had insisted on it, and some said that it had

been the only available housing option when they had to move due to changing life circumstances. These respondents said that they felt out of place and would like to live somewhere else if they got the opportunity.

Experiences Providing Both Opportunities and Constraints to Live a Life That One Values

Life events sometimes caused mixed feelings because they concurrently made life better in some respects and worse in others. For example, a life event could increase autonomy and decrease closeness or connectedness at the same time.

The death of a spouse was a life event that could evoke mixed feelings. This was especially the case if the spouse had been ill for a long time before dying. Several participants said that while they were grieving the death of their long-time partner, they also felt a sense of relief, for reasons such as being exhausted from worrying about their spouse's deteriorating health or being the primary caregiver which can lead to a rather restricted life. One participant illustrated this by saying:

If he [her husband] were still alive, I think my life would be quite boring because I would be taking care of him. Regardless of whether he was living at home and I was looking after him myself, or whether he was in an institution, I would still have to go there daily and keep in touch with him or his carers. I think my life would have been quite monotonous (P20).

Another life event that could cause mixed feelings was retirement. For some participants, for example, retirement meant that they were finally free to organise their days as they wished.

At the same time, they had a job in which they had felt useful, and which had been of benefit to other people or to the development of their workplace. Many participants also mentioned that they missed the social life that working life had provided. One participant described her mixed feelings towards retirement by saying:

It becomes less stressful [after retirement], and it's good of course that you can choose more freely, which is healthy [...]. [But after retirement], you don't have that dynamic human contact [...] (P4).

Just as retirement was perceived by some participants as a life event that evoked conflicting feelings, so was relocating to senior housing. For example, several participants said that although they felt fortunate to have found the perfect home to suit their personal preferences in a supportive environment, there was more variation in the age and health status of the residents than they had expected. Living in the same residential facility as people in very poor health could make them feel out of place or generally dissatisfied with aspects of their living environment.

Discussion

This research set out to explore how senior housing residents experience life events and associate such changes with their current quality of life. In line with previous research, our findings suggest that it is rarely the life event itself that affects a person's quality of life (e.g. Pocnet et al. 2016; Ventegodt et al. 2006). Life events that provided our participants with opportunities to live the lives they valued, such as feeling socially connected and developing as a person, were perceived to improve their quality of their life. Conversely, disruptive life events that restricted their ability to live the kind of life they valued, such as loss of social closeness or independence, detracted from their assessment of their quality of life. Although their experiences of life events involved different aspects of the principles that are part of the life course perspective, two of the principles were much more prominent in our participants' accounts, namely the principles of linked or interdependent lives and human agency in choice-making. The discussion section will therefore be centred around these two principles.

Regardless of which life event our participants talked about in relation to their current quality of life, the subject of social relationships came up. This finding makes visible the way in which people's lives are embedded in various social relationships with relatives and friends throughout life (Elder 1994). Individuals thus position themselves in relation to one another (Grenier 2012: 31) and are accordingly affected by each other's actions, experiences, and transitions throughout life (Elder & Shanahan 2006: 696).

Life events that contributed to feeling socially connected were perceived by our participants to add quality to life, such as taking up a

rewarding hobby, because they were able to socialise with people who shared their interest. Taking up a hobby provides a regular forum for socialisation, which can contribute to quality of life (Gabriel & Bowling 2004). In addition, becoming part of a group promotes a sense of belonging, builds rewarding relationships and enhances self-esteem, but can also reduce stress and isolation in old age (Ismail et al. 2021).

Engaging in social activities was clearly important to our participants. Such activities can improve psychological well-being by allowing older adults to maintain an interest in life, keep busy and active, and meet other people (Gabriel & Bowling 2004). A life event that had facilitated participation in social activities and a richer social life for a number of participants was moving into senior housing. Some had experienced life events prior to the move that had resulted in reduced social closeness, such as widowhood. For some of the participants the move had provided an opportunity to make new social connections, maintain existing ones or reconnect with old friends. Relocation was therefore perceived to enhance quality of life. Previous research has shown that early social engagement after relocation helps residents make new friendships, integrate better (Lotvonen et al. 2018), and maintain a better quality of life (Roberts & Adams 2018; Silva-Smith et al. 2011).

While some of the life events that added quality to our participants' current lives related to quality friendships, others related to entering into a serious relationship, such as marriage. Previous research suggests that marriage may represent a turning point that has a major impact on individuals' perceptions of what is important in terms of quality of life (Plagnol & Scott 2011), and has been positively associated with mental well-being (Cleland et al. 2016a; Cleland et al. 2016b). Participants who were married said that one of the main reasons they perceived marriage as a life event that made their current life better was that it had been followed by other interrelated positive life events, namely having children and grandchildren.

Although many of our participants talked about life events that contributed to high quality social relationships characterised by connectedness or support, several also talked about events that led to a reduction in the quality or loss of close social relationships. For example, developing a chronic disease could lead to social withdrawal. These individuals lacked close relationships in general, but also with their neighbours. This

indicated that they perceived a lack of social support, which can have negative effects on quality of life (Pocnet et al. 2016). Several of our participants also said that the death of a spouse or other significant person could also lead to reduced closeness. For some, it meant that they had lost the only person they felt close to and a particular connection with. The loss led to feelings of bereavement, which can lead to poor psychological well-being and a poor outlook on life (Gabriel & Bowling 2004). These respondents said that they found it difficult to cope with the grief. Lacking strategies to cope with difficult life events, such as receiving compassion and support from others, can reduce quality of life (Ferreira et al. 2021).

We now turn to another finding in our data – human agency in decision-making. Overall, our participants emphasised that it had been important for them to have the freedom to make autonomous decisions regarding life events that could shape their lives in the desired direction, such as the choice of education or to relocate to senior housing. Many of them expressed gratitude for having had the freedom to make these choices without unwanted interference from others, namely to have autonomy (Shrira 2012). Autonomy can be regarded as an important domain of quality of life, but also a basic human need (Wiggins et al. 2004). Participants who had been able to pursue an education or profession of their choosing often talked about how this decision had led to other positive life events that had contributed to a good life, including financial security. These individuals had made purposeful decisions that eventually allowed them to achieve their goals. This brings the process of cumulative advantage to mind – they had their mind set on what they wanted to become, which serves as an incentive for action (Hutchison 2019), and accordingly followed a pattern of behaviour that had lasting positive consequences (Elder 1998; Elder & Shanahan 2006: 682).

A positive consequence of what can be interpreted as cumulative advantage was that it had allowed these participants to choose how and where to live in old age, which was one of the reasons why they had chosen to relocate to senior housing. For many, the relocation was perceived to make life better because their current needs were met, including the ability to have a social and active lifestyle, which is fundamental in the pursuit of high quality of life for many in old age (Tyvimaa 2011). They

valued an active everyday life, particularly physical activities, because they wanted to stay healthy for as long as possible and remain independent. To sustain a higher quality of life among senior housing residents, the residential staff should consider each resident's needs, values, autonomy, goals, and preferences (Silva-Smith et al. 2011).

However, several participants said that they had only relocated to senior housing due to circumstances beyond their control, such as the death of a spouse, and that they felt out of place and would rather live somewhere else. This suggests that they found it difficult to adapt to their new accommodation – not only did they find the move itself stressful, but they had also experienced stressful events prior to the move that required even more adjustment (Ewen & Chahal 2013).

Thus, although it is usually assumed that individuals have agency to make choices and act within the opportunities and constraints of the context in which they live (Elder 1998), our findings indicate that there may be situations in which people lack such agency. Just as relocating to senior housing could be such a situation, having been sent away as a war child due to World War II could also be perceived as an undesirable experience that detracted from quality of life. Events that are out of one's control are more likely to cause distress (Zautra & Reich 1981). Enwo et al. (2021), in keeping with Yilmaz and Tekin (2018), suggest that to improve quality of life in old age, it is important to consider and address the impact of adverse childhood events. According to Vente-godt et al. (2006), the damage inflicted by such events can heal successfully if they are processed, which can subsequently enhance quality of life, even in old age.

Thus far, we have discussed the principles of linked lives and human agency separately. However, as noted earlier, the two are interrelated, and this interrelation was evident in our findings. For example, a number of life events that could evoke conflicting feelings contained elements of both concepts. For instance, some of our participants said that retirement gave them more freedom to choose what they wanted to do with their time, but at the same time they missed the social life that had been a vital part of their working life. The impact of life events is clearly anything but straightforward because many life events seem to provide individuals with conflicting emotions (Cleland et al. 2016a). Some life events, such as relocating to senior housing, can

trigger both positive and negative stress responses; while the move can evoke fears of losing one's independence, for example, it can concurrently be perceived as an opportunity to increase social contacts (Ewen & Chahal 2013).

As regards the methodology used in this study, it has both limitations and strengths. In terms of limitations, qualitative methods involve interpretations of the data, and hence researcher and participant perceptions of what life events represent may differ (Swain et al. 2020). In addition, although we explicitly asked the participants about both positive and negative life events that they felt had influenced their quality of life, it is possible that some of them reported fewer positive events because their psychological outlook on life was less positive, or conversely, that some reported more positive than negative events because their outlook was more optimistic (Gabriel & Bowling 2004). Another limitation that needs to be addressed is the issue of saturation, that is when the data have reached *sufficient* conceptual depth to allow the researcher to theorise (Nelson 2017). While we addressed the five criteria for reaching sufficiency – range, complexity, subtlety, resonance, and validity – we cannot say with certainty that we managed to achieve it.

In terms of strengths, the life course perspective helped us to identify life course patterns in different life phases and transitions (Alwin 2012), but also to put the findings into context. Furthermore, using an abductive approach enabled us to maintain the balance between theorising and the empirical data (Thompson 2022). This approach also allowed us to consider unexpected themes in our data that deviated from existing research and theory, such as those relating to personal development and needs.

Conclusions

Our findings suggest that life events may influence quality of life in old age, particularly those related to social relationships and autonomy. Life events that are perceived to add quality to life can contribute to personal development and social connectedness, and involve a strong sense of human agency. Life events that are perceived to detract from quality of life are those that may cause anxiety, reduce a sense of autonomy, and

involve loss of social closeness. However, some life events may be perceived in parallel as improving life in some respects and worsening it in others, as some experiences may, for example, increase autonomy but at the same time lead to a loss of closeness or connectedness. Overall, our findings support the view that good social relationships are one of the most central domains of quality of life for older adults (Gabriel & Bowling 2004).

Moving into senior housing is a life event that appears to influence the quality of life of older adults. Since many people move to senior housing in search of higher quality of life and hope that senior housing can provide the opportunity to age in place, it is important that it can provide an environment that supports autonomy and a sense of belonging – that is, a living environment that meets their needs. In terms of future research, it would be important to extend this line of enquiry and further explore how good quality of life in old age can be supported. Based on the provisional findings of our small-scale qualitative study, we suggest that further research be undertaken to explore how human needs relate to life events. Further research could also explore how personal development can be supported across the life course.

Conflicts of interest

The authors do not have any potential conflict of interests to declare.

Data availability statement

The analysed and interpreted data presented in this article are not readily available because it is in Swedish. The data will be available in English before the end of 2024. Requests to access the data should be directed to ann-louise.siren@folkhalsan.fi.

Ethics approval

The present study is linked to the ongoing study BoAktiv, which has been approved by the ethical review board in Humanities and Social and Behavioral Sciences, Helsinki University, Finland (ethical review statement 34/2017).

Consent to participate

Participants signed an informed consent after receiving written and oral information regarding the aim of the research.

Consent for publication

Participants approved dissemination of the findings.

Funding

This work was supported by Samfundet Folkhälsan, Jan Magnus Jansson Foundation and the Academy of Finland [grant no. 349336 to MvB]. The funders had no role in designing or conducting the study or interpreting the results.

Corresponding Author

Ann-Louise Sirén, Folkhälsan Research Center, Topeliuksenkatu 20, 00250 Helsinki, Finland. Email: ann-louise.siren@folkhalsan.fi

References

- Alwin, D. F. (2012). Integrating varieties of life course concepts. *Journals of Gerontology – Series B Psychological Sciences and Social Sciences* 67(2): 206–220. doi: 10.1093/geronb/gbr146
- Clarke, V. & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology* 12(3): 297–298. doi: 10.1080/17439760.2016.1262613
- Cleland, C., Kearns, A., Tannahill, C. & Ellaway, A. (2016a). Home truths: Are housing-related events more important for residents' health compared with other life events?, *Housing Studies* 31(5): 495–518. doi: 10.1080/02673037.2015.1094565
- Cleland, C., Kearns, A., Tannahill, C. & Ellaway, A. (2016b). The impact of life events on adult physical and mental health and well-being: Longitudinal analysis using the GoWell health and well-being survey. *BMC Research Notes* 9(1): 1–9. doi: 10.1186/s13104-016-2278-x

- Elder, Jr. G. H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly* 57(1): 14–15. doi: 10.2307/2786971
- Elder, Jr. G. H. (1998). The life course as developmental theory. *Child Development* 69(1): 1–12. doi: 10.1111/j.1467-8624.1998.tb06128.x
- Elder, Jr. G. H. & Shanahan, M. J. (2006). *The Life Course and Human Development* (Volume 1, 6th ed., pp. 665–715). R. M. Lerner (ed.). Hoboken: John Wiley and Sons Inc.
- Enwo, O. O., Player, E., Steel, N. & Ford, J. A. (2021). The impact of life events on later life: A latent class analysis of the English Longitudinal Study of Ageing. *Journal of Public Health* 43(2): 180–187. doi: 10.1093/pubmed/fdaa002
- Ewen, H. H. & Chahal, J. (2013). Influence of late life stressors on the decisions of older women to relocate into congregate senior housing. *Journal of Housing For the Elderly* 27(4): 392–408. doi: 10.1080/02763893.2013.813428
- Fernández-Ballesteros, R. (2011). Quality of life in old age: Problematic issues. *Applied Research in Quality of life* 6: 21–40. doi: 10.1007/s11482-010-9110-x
- Ferreira, C., Barreto, M. & Oliveira, S. (2021). The link between major life events and quality of life: The role of compassionate abilities. *Community Mental Health Journal* 57: 219–227. doi: 10.1007/s10597-020-00638-z
- Folkhälsan. (2021). *About Folkhälsan*. Available on <https://www.folkhalsan.fi/en/om-folkhalsan/> (Accessed: November 09, 2023)
- Gabriel, Z. & Bowling, A. (2004). Quality of life from the perspectives of older people. *Ageing & Society* 24(5): 675–691. doi: 10.1017/S0144686X03001582
- Grenier, A. (2012). *Transitions and the Lifecourse – Challenging the Constructions of ‘Growing Old’*. Bristol: The Policy Press.
- Hutchison, E. D. (2019). An update on the relevance of the life course perspective for social work. *Families in Society: The Journal of Contemporary Social Services* 2019 100(4): 351–366. doi: 10.1177/1044389419873240
- Ismail, A., Razak, F. & Faisal, W. N. M. (2021). Appraising a sense of community in designing senior housing for elderly quality of life. *Journal of Architecture, Planning and Construction Management* 11(1): 14–36.
- Lahti, A. M., Mikkola, T. M., Salonen, M., Wasenius, N., Sarvimäki, A., Eriksson, J. G. & von Bonsdorff, M. B. (2021). Mental, physical

- and social functioning in independently living senior house residents and community-dwelling older adults. *International Journal of Environmental Research and Public Health* 18(23): 1–11. doi: 10.3390/ijerph182312299
- Lotvonen, S., Kyngäs, H., Koistinen, P., Bloigu, R. & Elo, S. (2018). Mental well-being of older people in Finland during the first year in senior housing and its association with physical performance. *International Journal of Environmental Research and Public Health* 15(7): 1331. doi: 10.3390/ijerph15071331
- Nelson, J. (2017). Using conceptual depth criteria: Addressing the challenge of reaching saturation in qualitative research. *Qualitative Research* 17(5): 554–570. doi: 10.1177/1468794116679873
- Nowell, L. S., Norris, J. M., White, D. E. & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods* 16(1): 1–13. doi: 10.1177/1609406917733847
- Plagnol, A. C. & Scott, J. (2011). What matters for well-being: Individual perceptions of quality of life before and after important life events. *Applied Research Quality Life* 6: 115–137. doi: 10.1007/s11482-010-9119-1
- Pocnet, C., Antonietti, J.-P., Strippoli, M.-P. F., Glaus, J., Preisig, M. & Rossier, J. (2016). Individuals' quality of life linked to major life events, perceived social support, and personality traits. *Quality of Life Research* 25: 2897–2908. doi: 10.1007/s11136-016-1296-4
- Roberts, A. R. & Adams, K. B. (2018). Quality of life trajectories of older adults living in senior housing. *Research on Aging* 40(6): 511–534. doi: 10.1177/0164027517713313
- Shanahan, M. (2000). Pathways to adulthood in changing societies: Variability and mechanisms in life course perspective. *Annual Review of Sociology* 27: 667–692.
- Shrira, A. (2012). The effect of lifetime cumulative adversity on change and chronicity in depressive symptoms and quality of life in older adults. *International Psychogeriatrics* 24(12): 1988–1997. doi: 10.1017/S1041610212001123
- Siltanen, S., Keskinen, K. E., Lahti, A. M., Rantanen, T. & von Bonsdorff, M. (2023). Active aging in senior housing residents and community-dwelling older adults: A comparative study in Finland. *Journal of Aging and Health* 36(5-6): 299–307. doi: 10.1177/08982643231186627

- Silva-Smith, A. L., Feliciano, L., Kluge, M. A., Yochim, B. P., Anderson, L. N., Hiroto, K. E. & Qualls, S. H. (2011). Practice concepts and policy analysis. *The Gerontologist* 51(3): 406–414. doi: 10.1093/geront/gnq117
- Swain, J., Carpentieri, J. D., Parsons, S. & Goodman, A. (2020). Using a life course perspective to understand early labor market exits for people in their late 50s living in the UK. *International Journal of Ageing and Later Life* 14(2): 163–192. doi: 10.3384/ijal.1652-8670.3285
- Theofilou, P. (2013). Quality of life: Definition and measurement. *Europe's Journal of Psychology* 9(1): 150–162. doi: 10.5964/ejop.v9i1.337
- Thompson, J. (2022). A guide to abductive thematic analysis. *The Qualitative Report* 27(5): 1410–1421. doi: 10.46743/2160-3715/2022.5340
- Tyvimaa, T. (2011). Social and physical environments in senior communities: The Finnish experience. *International Journal of Housing Markets and Analysis* 4(3): 197–209. doi: 10.1108/17538271111152997
- Van Leeuwen, K. M., Van Loon, M. S., Van Nes, F. A., Bosmans, J. E., De Vet, H. C., Ket, J. C., Widdershoven, G.A.M. & Ostelo, R. W. (2019). What does quality of life mean to older adults? A thematic synthesis. *PLoS One* 14(3): e0213263. doi: 10.1371/journal.pone.0213263
- Ventegodt, S., Flensburg-Madsen, T., Andersen, N. J. & Merrick, J. (2006). What influence do major events in life have on our later quality of life? A retrospective study on life events and associated emotions. *Medical Science Monitor* 12(2): 9–15.
- Walker, A. & Lowenstein, A. (2009). European perspectives on quality of life in old age. *European Journal of Ageing* 6: 61–66. doi: 10.1007/s10433-009-0117-9
- Wiggins, R. D., Higgs, P. F. D., Hyde, M. & Blane, D. B. (2004). Quality of life in the third age: Key predictors of the CASP-19 measure. *Ageing & Society* 24: 693–708. doi: 10.1017/S0144686X04002284
- Xavier, F. M. F., Ferraz, M. P. T., Marc, N., Escosteguy, N. U. & Moriguchi, E. H. (2003). Elderly people's definition of quality of life. *Revista Brasileira de Psiquiatria* 25(1): 31–39. doi: 10.1590/S1516-44462003000100007
- Yilmaz, F. & Tekin, R. N. (2018). Effects of early life factors on the health and quality of life of older adults. *Psychogeriatrics* 18(1): 30–35. doi: 10.1111/psyg.12278
- Zautra, A. J. & Reich, J. W. (1981). Positive events and quality of life. *Evaluation and Program Planning* 4: 355–361. doi: 10.1016/0149-7189(81)90034-3

