

Add an asterisk to each one listed in the main references list and key to Endnote explanation “*indicates articles included in the analysis”

(Alex, Hammarstrom, Gustafson, Norberg, & Lundman, 2006; Aléx & Lundman, 2011; Andersson, Hallberg, & Edberg, 2008; Behm, Ivanoff, & Zidén, 2013; Caldas & Berterö, 2007; Carlsson, Berg, & Wenestam, 1991; Dahlin-Ivanoff, Haak, Fange, & Iwarsson, 2007; Darviri et al., 2009; Elias & Lowton, 2014; Fänge & Ivanoff, 2009; R. Fischer, Lundman, & Norberg, 2010; R. S. Fischer, Norberg, & Lundman, 2008; Fleming, Farquhar, Brayne, & Barclay, 2016; Freeman, Garcia, & Marston, 2013; Gilbert, Hagerty, & Taggert, 2012; Granbom et al., 2014; Graneheim & Lundman, 2010; Green, Sixsmith, Dahlin Ivanoff, & Sixsmith, 2005; Groger & Leek, 2008; Haak, Fange, Iwarsson, & Ivanoff, 2007; Haak, Ivanoff, Fänge, Sixsmith, & Iwarsson, 2007; Hauge & Heggen, 2008; P. Hedberg, Brulin, & Alex, 2009; Pia Hedberg, Gustafson, Brulin, & Alex, 2013; Holston & Callen, 2017; Hovbrandt, Fridlund, & Carlsson, 2007; Hutnik, Smith, & Koch, 2012; Koch, Power, & Kralik, 2007; Koch, Turner, Smith, & Hutnik, 2010; Larsson, Haglund, & Hagberg, 2009; Loe, 2010; Löfqvist et al., 2013; Ludvigsson, Milberg, Marcusson, & Wressle, 2015; Mackowicz & Wnek-Gozdek, 2017, 2018; L. K. Manning, Leek, & Radina, 2012; I. Nilsson, Lundgren, & Liliequist, 2012; M. Nilsson, Sarvimaki, & Ekman, 2000; Nosraty, Jylhä, Raittila, & Lumme-Sandt, 2015; Nygren, Norberg, & Lundman, 2007; Pascucci & Loving, 1997; Power, Koch, & Kralik, 2006; Scelzo et al., 2018; Sixsmith et al., 2014; Stones & Gullifer, 2016; Wand, Draper, Brodaty, & Peisah, 2018; Westerbotn, Fahlstrom, Fastbom, Agüero-Torres, & Hilleras, 2008; Wondolowski & Davis, 1991; Wong et al., 2014)

Abstract

Advances in health care mean that we can now treat diseases that once cut lives short.

However, the increase in life expectancy has not been matched by improvements in quality of life. The World Health Organisation warns us that all countries should prepare to meet the challenges of an aging population and this is integral to the United Nations 2030 Agenda for Sustainable Development. This may require a shift in attitude towards aging. We aimed to use meta-ethnography to explore the experience of adults living beyond the age of 80.

Our conceptual model illuminates the phenomenon of connection in older age and reflects on the *paradox of time*: ephemeral, yet interminable. Our findings encourage us to reflect on the influence of enlightenment philosophies that underpin the desire for autonomy at all costs. Our study challenges the stereotypes of old age and has the potential to influence people's perspectives towards aging.

Key words

meta-ethnography; older people; metasynthesis; research, qualitative.

Advances in health and social care mean that we can now treat diseases that once cut lives short. The UK Office for National Statistics predicts that 1 in 12 people will be more than 80 years old by mid-2039 (Office-for-National-Statistics, 2017). Although the World Health Organisation (WHO) describes increased longevity as a triumph of health and social care, this comes with the proviso that, ‘all countries need to be prepared to address the consequences’ (World-Health-Organisation, 2019). The increase in life expectancy has not been matched by an increase in ‘*Healthy* life expectancy’ (Office-for-National-Statistics, 2017). In the UK, estimates for 2015-17 show that an English male living to 80 years is likely to live 16 years in ‘not good’ health, and an English female living to 83 years would live 19 years in ‘not good’ health.

Preparing for an aging population is integral to the United Nations 2030 Agenda for Sustainable Development, and this may require an ‘attitudinal shift on aging and old age’ (Dugarova, 2017). Understanding what it is like to live to extreme age has the potential to influence people’s actions and perspectives towards aging and encourage people to consider a health and social agenda for an aging population. Qualitative research can allow us to understand and articulate people’s experience in order to inform health and social care. The WHO now uses qualitative evidence synthesis (QES) to inform guideline development, and to support worldwide health policy (World-Health-Organisation, 2014). The World Health Organisations Global Strategy and Action Plan on Aging aims to synthesize evidence on aging in order to provide information on the needs and preferences of older people (World-Health-Organization, 2017). Using published search terms (Fran Toye, Seers, & Barker, 2019) we identified 133 QES that explored the experience of older adults but none of these uniquely explored the experience of adults over the age of 80. Our innovation is to conduct the first QES that specifically explores the experience of adults living beyond the age of 80.

Methods

There are various methods for synthesising qualitative research (Barnett-Page & Thomas, 2009; Dixon-Woods, Booth, & Sutton, 2007; Sandelowski & Barroso, 2007). Some methods amalgamate and *describe* findings and others (such as meta-ethnography), aim to develop *conceptual* understandings. We planned to develop a line of argument synthesis to make ‘a whole into something more than the parts alone imply’ (Noblit & Hare, 1988). We used the methods refined specifically for conducting large meta-ethnographies (F Toye et al., 2013a; F Toye et al., 2014)

We searched four online medical databases (Medline, Cinhal, Psycinfo and Embase) from inception to December 2018 to identify primary studies that explore the experience of extreme age. We combined thesaurus headings for *qualitative research* ("FOCUS GROUPS"/ "ANTHROPOLOGY, CULTURAL"/ "QUALITATIVE RESEARCH"/ "INTERVIEWS AS TOPIC"/ "ATTITUDE TO HEALTH"/ "NURSING METHODOLOGY RESEARCH"/) with free text terms to identify studies of people over the age of 80: octogenarian OR nonagenarian OR centenarian; extrem* ADJ3 (old* OR age* OR elder* OR geriat* OR veteran); very ADJ3 (old* OR age* OR elder* OR geriat* OR veteran); "fourth age*" OR "forth age*" OR "4th age*". We limited our search to studies written in English. In order to see if any additional studies would add further insight, we expanded our search post hoc to include studies identified in the references lists of included studies.

QES hinges upon the abstraction of robust ideas from an adequate pool of primary studies. One reviewer screened potential studies and if they had any doubt about its relevance, discussed this with a second reviewer. When we had agreed which studies were relevant, two reviewers quality appraised studies as either: satisfactory, key (conceptually rich) or fatally flawed (Dixon-Woods, Sutton, et al., 2007).

When we had decided which studies to include, two reviewers read the studies in alphabetical order by author to identify the *ideas* or concepts. One reviewer then rewrote these ideas in the first person: we have found this a powerful way to effectively distil the essence of an idea. Next, two reviewers *translated* the ideas across studies through comparison, sorting them into categories of ideas with a shared essence. This distilling process is integral to conceptual forms of qualitative research (Tavory & Timmermans, 2014). One reviewer then wrote a first person statement to capture the essence of each category and printed these on postcards. All reviewers independently organised the postcards by further distilling their essence. They then met to compare and discuss the final QES findings. We aimed to develop a line of argument that would allow further insight into the experience of extreme aging. The final analytic stage of meta-ethnography, *synthesising translations* involves organising QES findings into an *interpretive order* or conceptual model. We used NVivo 11 software to keep track of the analytical decisions (Nvivo, 2010).

We used the GRADE-CERQual framework (Lewin et al., 2018) to rate our confidence in findings. GRADE-CERQual suggest four domains: (1) '*Methodological limitations*'; (2) '*Relevance*'; (3) '*Adequacy of data*' (the 'degree of richness and quantity of data supporting a review finding'); (4) '*Coherence*' (consistency across primary studies); and finally, an overall rating of confidence (high, moderate, low, very low). We applied the GRADE-CERQual assessment of confidence to our individual QES findings, but not to our conceptual model, as GRADE-CERQual was not designed for this purpose.

Search Findings

Figure 1 illustrates the number of studies identified, screened and included. We screened the title and abstract of 2206 records and 58 full texts. We agreed that eight studies were outside our review scope, and four studies offered limited analytical insight (see supplementary file 1). We included 46 primary studies in our initial analysis and three additional studies in our post hoc analysis (n= 49). The studies included in our analysis are listed in table 1 and indicated with an asterisk in the reference list. Table 1 shows the author, year of publication, country, age range, number of participants, study aim, data collection, analytic methods and quality assessment. The included studies explored the experience of 1183 participants from a range of countries: Australia, Finland, Germany, Greece, Hong Kong, Italy, Norway, Poland, Brazil, Sweden, UK, USA, Latvia, and Hungary. Nine of the 49 studies included participants from the European ‘Enabling Autonomy, Participation and Well-Being in Old Age: The Home Environment as a Determinant for Healthy Aging’ (ENABLE-AGE) study. The ENABLE-AGE study incorporated interviews with 190 extremely old participants from Germany, UK, Hungary, Latvia and Sweden. Similarly, 9 of the 49 studies included participants from the Swedish Umea 85+ project which aimed to describe the health and living conditions of 253 people over the age of 85.

Synthesis Findings

We identified 507 ideas from 49 primary qualitative studies. We distilled the essence of these ideas into 50 conceptual categories (supplementary file 2). We then further distilled the essence of these categories into nine QES findings (table 2).

We illustrate each QES finding with a narrative exemplar. We conceptualised the nine QES findings into four themes that underpinned our line of argument: (a) experiencing

discrepancy; (b) negotiating connection; (c) the paradox of time; (d) discourse on successful aging.

Experiencing discrepancy

The essence of this theme is the variance, or discrepancy in the experience of living into extreme age. We distilled two discrepant poles of experience: feeling *vital* or feeling *diminished*.

I am vital. The essence of being vital was described as living an enriched and happy life into older adulthood. Vitality is “that immaterial force or principle which is present in living beings or organisms and by which they are animated and their functions maintained” (Oxford English Dictionary). Life is still wonderful. I am still myself despite physical change. I don’t feel any different. I have the “same elements” that I have always had (Nosraty et al., 2015).

I feel wonderful. I don’t feel that I’m 100 years old. I don’t feel any different than fifty years ago. . . Well, to me it’s just a process of one day after another, you know, and then you get there. I mean, you don’t feel any different (Groger & Leek, 2008).

Vitality is underpinned by a sense of awe and wonder at the world and a perception of your own place in it.

Yes, you should take everything as it comes ... nothing is that important ... I am just a little dot in the universe and still I am wonderful ... a wonderful creation (Graneheim & Lundman, 2010).

There is a sense of pride and strength in living to a very old age. I am proud of my achievements. I am still *vital* with my aging body. I feel whole, confident and joyful. I am strong, resilient, energetic and competent. I still believe in myself.

You have to have some kind of strength to handle it so you don't break . . . I probably have had a strong mind . . . I have been mentally and physically strong, I have been both and I still have some kind of strength in both parts (Nygren et al., 2007).

Being vital also means that you are not too old to make a social contribution and have responsibilities. You are still useful and generous to others and maintain your responsibilities.

I think my life is to be in the place of a servant . . . as far as I gain strength . . . to help others and be at hand (R. Fischer et al., 2010).

This finding highlights improvements and advantages that can come with older age (a) It can bring freedom from the duties and worries of youth; (b) it can bring increased wisdom for the new generations: I am wiser today (Nygren et al., 2007): "Growing old is like climbing a mountain. You get a bit out of breath, but you get a better view." (Alex et al., 2006).

You learn to accept other people . . . That's a part of aging well . . . regardless of whether you like it or not . . . old age is permissive; it accepts other people as they are (Nosraty et al., 2015).

I am diminished. In contrast to feeling vital, this describes a sad and diminished life into older adulthood and the experience of an aging body in decline. Older people felt vulnerable; that they could no longer rely on their own body. They described feeling old.

I'm afraid, because my legs are so weak. . . and the worst of it is that I have some dizziness too and that makes me anxious, I'm afraid of falling over . . . [a friend is] accompanying me to the dentist's . . . but I'm dreading it (I. Nilsson et al., 2012)

Being diminished meant feeling insignificant or invisible. People wanted their story to be heard by others: I feel abandoned, cast aside by society and invalid. I feel lonely, detached and forgotten. No one calls or visits. No one seems to care. No one sees who I am and who I was. I am unrecognized and misunderstood.

Everyone has their own business to attend to, and no one needs an old person. I would like to gather those who live here and tell them my story so they will know who I am and who I was (Graneheim & Lundman, 2010).

This feeling was exacerbated because they felt that Society saw bodily decline as inevitable and that older people could no longer make a contribution.

I have a lot of opinions . . . that things should have been done in different ways. But now I'm far too old, nobody cares what an old lady thinks (I. Nilsson et al., 2012)

At the same time (and paradoxically), people experienced the social expectation that you should age *well*: you are expected to keep active, keep going, be independent, and not to give in. If you cannot meet this expectation then you feel that you have failed. Nilsson and colleagues highlight the pressure on older adults to live up to this expectation (M. Nilsson et al., 2000). Being diminished incorporated a feeling that life has not turned out as expected. People described sorrow and regret; Life is dismal and I have lost my sense of self. I just exist, rather than live. All the days seem the same. Life was happier in the past.

You just wake up, get dressed, and wait for the day to end, and there's not much more to do (P. Hedberg et al., 2009)

Death and loss has become a regular feature of life. Contemporaries have died; friends and family have gone (even children). The strongest connections are to those who have now passed away. It can feel very hard to be the only one left living.

I don't feel lonely, but I do feel that something is missing. For the only one left, it can be hard to see meaning in life and to retain a zest for life (Graneheim & Lundman, 2010).

Feeling diminished is accompanied by fear of further decline, poverty and financial dependence.

There's hardly anything left from my pension for food. Often there's hardly anything left by the end of the first week (Sixsmith et al., 2014).

Negotiating Connection

The essence of this theme is the need to negotiate the tension between being connected to a greater whole, yet at the same time remaining beholden to no one. At times, people appreciated time alone and distinguished being *alone* from feeling *lonely*: 'I am not a hermit but I appreciate time alone' (Graneheim & Lundman, 2010). Some described how the benefits of connection should outweigh the costs (Darviri et al., 2009).

I am often glad to be able to close the door behind me. To have nobody calling me, and nobody who wants something from me . . . [my best friend] asks me, “Hey, do you feel like seeing me today?” Yes, sometimes. (Sixsmith et al., 2014).

I am connected to a greater whole. This describes the person connected to something outside themselves through a series of concentric circles: family, society, humanity, physical world, and (for some) faith in God. Family is the closest connection and is played out at two levels: (a) in the moment, and (b) across time. Family, particularly grandchildren, bring joy in the moment. This connection is maintained by keeping up with family news and interests even when they are no longer geographically close.

Our grandchildren . . . have definitely enriched our lives . . . it was a blessing. . . .
One grandchild said . . . “Grandpa, when I go home . . . tomorrow, you will be so bored and have nothing to do.” [Laughs] And I thought yes, that was well said
(Nosraty et al., 2015).

Family also provides connection that extends across time: even death does not part you from family. Family connects you to the past and to the future; it continues. I created a family, cared for them and I still worry about them.

To see my children carry on, lead good lives and be happy. . . I want my grandchildren to grow up and be happy... I don't wish for them to give me things, I just wish for them when they come and give you a big love and a big kiss (Power et al., 2006).

Social relationships also provide a fundamental connection to the world. It is important to be sociable, to have good relationships and to be generous with your time. You can find joy and strength in companionship at any age. Meeting other people is enriching; it creates new ideas, insights and lifts your spirits.

The only real necessity beyond food, drink and shelter is friendship, and if technology can enable this, it can be important' (Loe, 2010).

Meaningful social connection ranged in intimacy from close friends to distant passers-by.

[When I am in town] there's a completely different movement . . . you feel that you're a part of the whole . . . it is like this, you are one among others. . . . Even if there isn't anybody I know . . . to be part of society (Haak, Ivanoff, et al., 2007).

Social connection mitigated the danger of loneliness.

I try to go out, sit in my garden, have a chat with my neighbours, my cousin's family sometimes comes over together with my cousin's grandchildren . . . I live alone but I never feel lonely(Mackowicz & Wnek-Gozdek, 2018).

Shared humanity also gave a sense of connection to a greater whole. We are all human. I am not distinct from others. We are all bound by nature and are powerless to change things. We are all mortal. We pass on our heritage.

Well I am also a human being . . . I do not downgrade any of my friends but also I do not accept to be downgraded, I also am a human being. . . . I am not [distinct], how should I be? (Darviri et al., 2009)

There is a sense that I am part of this world and I should be curious and concerned about what is going on in it. Keeping up with world events and politics means that I maintain an ethical bond with humankind that underpins my connection to it.

You've got to keep being interested . . . some of my friends, before they died . . . they never read a paper or anything like that. . . they sort of pulled down the shutters
(Stones & Gullifer, 2016).

Contact with the world of nature also provided a vital connection; to go outdoors and to feel at one with nature makes you feel alive and part of something greater than yourself.

It is the most wonderful thing to go there and to be there . . . totally alone with nature . . . it is pleasant, just pleasant . . . you relax . . . when you were younger you didn't think in that way (Nygren et al., 2007).

Finally, for some, faith in God also provided an important connection to a greater whole: faith is, and has been, a constant and present companion. Faith connected people to the past and to the future. It helped during hard times and gave a sense of community.

I've been . . . going to that church when I was 25 years old—that's 75 years I've been a part of that church!" (L. K. Manning et al., 2012)

I am beholden to no one. In contrast to connection, people described the need for personal autonomy, individuality and self-determination. Independence and freedom is important: I want to make my own decisions and make my own choices. I want to do things my own way.

Well, old age is being able to do what you want. . . When nobody bosses you around and you can do what feels good. . . . I can decide for myself what I like and what I do. Nobody can tell me what to do. Except my wife (Nosraty et al., 2015).

Being beholden to no one meant not wanting to be at the mercy of others. Some feared dependence more than death.

Worst of all would be to end up at a hospital or nursing home . . . I don't want to see that day — I'm beginning to be a bit afraid about getting worse for every year that passes and maybe having to end up in a nursing home, it would be terrible (M. Nilsson et al., 2000)

There was a tension between the need for independence and yet at the same time relying on others: I can't do everything that I used to be able to do, and at times, my life *is* in the hands of others.

It's the council that decides when you have a pee [laughter] . . . you have to see to it that you pee when they come . . . they come around three o'clock and then I usually have a pee (Haak, Fange, et al., 2007).

There was a sense of resistance to encroaching dependence, even when the battle seemed to be lost. I will only accept help on my own terms. I will make the decision when to relinquish control: I will keep a tight hold of the reins. I will think carefully about what I am prepared to delegate: "Everything to do with boring things I gladly accept" (Fänge & Ivanoff, 2009).

At the same time, there was a sense that you needed to know your limits and accept help if necessary. It is a trade-off. Some chose to pay for extra help or trade tasks with other people

[it] doesn't mean I've let go of the reins up here [pointing to her head]. . . it's a sort of trade off . . . I get to keep independence longer . . . I don't mind other people doing these things . . . it allows me to be able to be at home. . . I need some things done so you just have to accept it (Stones & Gullifer, 2016).

The Paradox of Time

This theme is underpinned by the paradoxical experience of temporal life. The paradox is that although time seems to stand still, it has passed, and is still passing, quickly: "One feels that the day ends before it begins" (R. S. Fischer et al., 2008). Time is experienced as ephemeral yet, at the same time, interminable. The Oxford English Dictionary describes *ephemeral* as 'beginning and ending in a day'; it describes the transitory nature of existence. In contrast, *interminable* is defined as that which 'cannot be bounded or ended; boundless; endless'; this describes the infinite nature of existence. Our findings show that this paradox is lived simultaneously in the moment yet also transcending the moment.

Living in the moment. Living in the moment means to appreciate and find value in life's 'little things': Catch the moment. Live in the here and now. Don't worry about tomorrow or dwell in the past. Allow the future to remain uncertain and lead a full life now.

It is this day that counts; yesterday is gone and tomorrow reaches beyond time and life (Graneheim & Lundman, 2010).

Living in the moment meant always keeping busy and avoiding boredom at all costs.

I'm terribly careful not to get up in the morning like: 'What for? What did I get up for; I've got nothing to do.' I would hate that . . . I find something for myself to do, preferably something I like (Sixsmith et al., 2014).

Activities to keep busy ranged widely from filling time with everyday routines, to being involved with more creative occupations. Routines could provide a distraction that kept you anchored in the moment. For some, these became 'rituals' to pass the time. Some described the minutia of their daily routines.

One becomes a creature of habit in that one does not want the modern; one proceeds in the old tracks. . . One doesn't jump over to new things that easily (Larsson et al., 2009).

At the other end of the spectrum, being engaged in the moment was described as being creative, curious and continuing to learn new skills.

I have to have something to get me up out of bed . . . I have a Monday card group . . . Tuesday night we go down to the beach and play cards . . . I go to meetings for the women's society . . . I volunteer . . . you are doing something worthwhile (Gilbert et al., 2012).

Living in the moment can mean that you consider the things that are important in life and devote time wisely to things that you value.

Yes, you see there are so many episodes you should be glad about, the happy things; and the other things you can ignore (Nygren et al., 2007).

Transcending the moment. In contrast to time lived in the moment, this describes how reminiscence allows you to transcend the finite. Reflection on the past can provide insight and allow reconciliation and peace. It can give you the strength to live in the moment.

I have had so many experiences, and especially those which enter a child's heart . . . they remain there and grow, more and more stable. . . this is something to live with and live for and it gives a feeling of safety in your everyday life (Nygren et al., 2007).

Strength can also come from reflecting on adversity. Life has been hard and I am proud of my struggle; adversity has made me stronger: 'life isn't all honey' (Hutnik et al., 2012).

Oh, what a hard blow it was [not to be able to continue education], a real shock . . . I had dreamt about [going to college] and hoped for it . . . so when I was denied . . . what a blow, I went around in the forest drifting aimlessly thinking about the injustice in the world . . . it was really hard . . . But it had something positive come from it because I have never thought that I should . . . forbid the children to do things (Nygren et al., 2007).

Ironically, it is through transcendence that a person recognises both the infinite and finite nature of existence.

Discourse on Successful Aging

This theme is underpinned by dominant ideologies on *successful* aging: lead an honourable life, have a good attitude, look after your body and use healthcare only when necessary.

Lead a Life of Honour. Successful aging meant leading a life of honour, which includes decency, modesty and hard work. An honourable life is one of moral virtue. Do your best, be good to other people and think of others first. Be humble and do not judge others.

Live a quiet life Do what you can for anybody . . . It is very important to help others because in helping other people, you are helping yourself. It was a wonderful life. Yes, it was a clean happy life (Power et al., 2006).

An honourable life includes being moderate and avoiding excess. There is a sense that in the past things were much simpler.

Today people live so extravagantly. They go out to eat. They don't cook at home . . . We were satisfied with half a loaf of bread. Today they want the whole loaf (Groger & Leek, 2008).

Participants described work as integral to an honourable life. Work gives you purpose and self-respect. To work is to take on a responsibility for yourself and others.

I can see other people are lying down . . . An old person should work and not sit in the corner if they have the strength to work, and the strength should be worked out, so to say. People should keep 'doing' (Mackowicz & Wnek-Gozdek, 2018).

Have a Good Attitude to Aging. Aging successfully also hinged on a certain attitude of mind: think positively, accept things as they are, be pragmatic and flexible, and yet (paradoxically) don't ever give in. Surround yourself with a positive atmosphere filled with sunshine, happiness and laughter. A positive attitude comes from within. Pass on your high spirits to others. Find joy despite adversity.

I see the positive in every day, and tomorrow is a new day . . . I take the day as it comes. I never dig myself into things. I always see things from the bright side (Pia Hedberg et al., 2013)

Being positive includes being thankful for what you have been given in life. Think of others who are worse off. Count your blessings.

There's a woman nearby, she's almost three years younger than me. She can't see, her hearing is bad and she can't walk . . . so sure I think I'm lucky that I still manage. I've been blessed and it's a great gift (I. Nilsson et al., 2012)

Being positive also meant keeping a sense of humour in the face of hardship: "if I didn't [have a sense of humour] I'd be dead a long time ago" (Groger & Leek, 2008). A good attitude incorporates acceptance: *que sera, sera* (what will be, will be). No one expects or plans to live this long and you must make the best of it.

I survived two world wars, I never expected to live for so long, I gave my clothes to others because I thought I would die in my 60s (Mackowicz & Wnek-Gozdek, 2017).

Having lived this long, you learn to take things as they come and just get on with it. Take each day as it comes. Accept that life is neither stable nor predictable and that you cannot always be in control. Things change and loss is part of life.

We just took it in our stride, I suppose. You have to don't you ... I'm afraid I am one of those resilient people. I don't just sit down and cry when it comes. I've just got to get on with it. . . . Just accept what comes (Hutnik et al., 2012).

Acceptance includes coming to terms with death, which is the natural course of things. I don't fear death. I am ready.

That day will come to us all . . . when you are younger you dread dying, you were afraid that you would be ill and die . . . but death entered then . . . father died suddenly . . . mother lived ten years longer . . . you have had death close many times, quick and unexpected(Nygren et al., 2007).

However, people were concerned about the manner of their death: I want to die in peace and free of pain. I want to keep my essential elements until the day I die and then slip away quickly and quietly: “ I'd be quite happy if I went [snaps fingers] suddenly like that (Fleming et al., 2016)”.

A good attitude to aging was also described as being pragmatic as your body changes. Adjust your expectations to avoid disappointment. Adapt and do things differently; be prepared to change.

I don't manage to get in the bathtub . . . I have a small washbowl in which I put my feet. I stand there naked and wash myself. This is the way we did it in earlier times, we also got clean. We did not choke in filth then (Sixsmith et al., 2014).

However, in contrast to pragmatism and acceptance, a good attitude was also described as *not giving in*: I will struggle to the bitter end.

As you go through life . . . you have to have the fortitude . . . you have to be willing to get up and go again if something knocks you down, I learned that early on to get back up and keep going (Gilbert et al., 2012).

Look After Your Own Body. Aging successfully also incorporated personal responsibility for looking after your own body to meet the challenges of aging.

Keep on moving . . . How many walks, how many miles haven't my wife and I walked . . . we bought an exercise bike . . . because it is good to move your body. And I think it is a very important part of aging, instead of just lying there (Nygren et al., 2007).

Looking after your body included eating healthily: eat simple sensible food in balance and moderation. Good food was described as part of the fabric of a *good* family.

We always had a pitcher of buttermilk and a pan of sweet potatoes on the table waiting for us when we got home from school (Holston & Callen, 2017).

Looking after your own body included dialogue about whether or not to access formal healthcare. People described the challenge of deciding, am I ill or is this a natural part of aging? Some described clinicians who they felt did not always make the right decision about whether to offer treatment or not: some blocked *necessary* treatment and “say ‘it’s your age’”(Elias & Lowton, 2014), whereas others might prescribe *unnecessary* treatment:

I am subjected to a full day of tests, and sometimes they keep me overnight to observe. This is frustrating, because I know I am fine . . . Then last week my [DR] suggested a precautionary measure . . . Was this really necessary? I don't know (Loe, 2010).

One participant suggested that doctors might offer inappropriate treatment because of an erroneous sense of duty or expectation:

These new-fangled medical things . . . they were giving her something so she could live five months. We both agree we don't want any part of that. We'd rather be comfortable . . . I won't take it. It is for the doctors, not for us. Their pride (Loe, 2010).

Conceptual Model: Being extremely old

Figure 2 illustrates our conceptual model, underpinned by our four essential themes: experiencing discrepancy, negotiating connection, the paradox of time and discourse on successful aging. Being an extremely old adult can be a markedly different experience: diminished or vital. We conceptualise being vitality as being connected, and diminished as loss of connection, . Central to our conceptual model is the complex process of *negotiating connection* with the world. We present a series of tensions between connection and disconnection: solitude/contact; intimacy/distance; dependence/independence; autonomy/heteronomy; self-determination/subjugation. We conceptualise these dual experiences as hinging around two poles: (a) I am beholden to no one: this is *being discrete* (separate; detached from others; individually distinct) and (b) I am connected to a greater

whole: this is *being continuous* (forming an unbroken whole without interruption). Finding a balance between the two poles (discretion and continuity) can be challenging because either can be construed as both negative *and* positive. For example, intimacy and subjugation both describe forms of being continuous, whereas distance and self-determination both describe forms of being discrete. Our conceptual model illustrates the paradox of time, ephemeral (finite), yet also interminable (infinite). This paradox is lived both in the moment and yet also transcending the moment through reminiscence. Time lived in the moment can be filled with routine and habit and yet it can also be a place of continuing learning and curiosity. Transcending the moment in time can provide strength to live in the moment. Finally, our conceptual model incorporates social discourse, or dominant ideology, related to *successful* aging: the expectation to live a life of honour, to have a good attitude and to look after your own body.

Confidence in our findings.

Details of our GRADE CERQual assessment are shown in table 2. We identified 3 studies post hoc which did not highlight any additional concepts, suggesting theoretical saturation (table 2).

Discussion

This unique QES is the first to explore the experience of adults beyond the age of 80 and there are some important implications for health and social care. The WHO emphasises the need to challenge stereotypes that define what it is to be “old” (World-Health-Organization, 2017). Understanding what it is like to live to extreme age can contribute to an ‘attitudinal shift’ (Dugarova, 2017) and influence people’s actions. Our first theme, *experiencing discrepancy*, challenges the stereotypes of aging and demonstrates that older adults can live vital lives alongside body changes. We have shown that older adults can, and do, participate and that they continue to make an important social contribution. We highlight

some advantages of being older: namely, freedom from social constraints and increased wisdom. As illustrated in the poem, ‘When I am an old woman I shall wear purple’: ‘I shall . . . run my stick along the public railings and make up for the sobriety of my youth’ (Joseph, 1961). This supports the WHO’s Global Strategy and Action Plan on Aging and Health by highlighting that although old age entails losses, ‘it can also be a period of personal growth, creativity and productivity’ (World-Health-Organization, 2017).

However, our theme, *experiencing discrepancy*, demonstrates a wide variance in quality of life lived beyond the age of 80. We illustrate the experience of feeling diminished and socially cast out. We highlight losses that are undiluted by age: loss of friends, spouses and children. We conceptualise being diminished as loss of connection, and vitality as being connected. To feel connected is underpinned by a fundamental human need to be recognised: ‘I would like to gather those who live here and tell them my story so they will know who I am and who I was’ (Graneheim & Lundman, 2010). This resonates with [Ebrahaim and colleagues who found that being *seen* by others and being treated with dignity were both important aspects of good health for frail older people; \(Ebrahimi, Wilhelmson, Moore, & Jakobsson, 2012\)](#)

Our findings support the need to be known, in particular by healthcare professionals. This resonates with other QES in older (but not so old) adults which support a person based approach that builds relationships through improved communication (Bradshaw, Playford, & Riazi, 2012; Dickson & Riddell, 2017; Elliott et al., 2016; Song & Kong, 2015a; Vaismoradi, Skär, Söderberg, & Bondas, 2016). This has profound implications for clinical practice. In particular, it encourages us to focus on hearing people’s stories and to ensure that these stories are ‘absorbed into the clinical encounter’ (Dickson & Riddell, 2017). In ‘The Renewal of Generosity’ Frank (Frank, 2004) argues that a patient-clinician relationship based on generosity and dialogue can provide consolation for both patient and clinician. Rather than

diagnosing and treating disease, The US National Institute for Aging suggest that clinicians start by asking older adults "What are your goals for your care?" Our findings support their view that older people 'care most about maintaining the quality of their lives' (National-Institute-on-Aging, 2017) and holding onto the 'same [essential] elements' (Nosraty et al., 2015). Health care professionals should focus on the body as a means, not an end, to living a healthy life.

Our model illustrates the complexity of negotiating connection. We conceptualise this as a precarious balance between opposing phenomenon (a) *being discrete* (separate; detached from others; individually distinct) and (b) *being continuous* (forming an unbroken whole without interruption). The process of balancing discretion and continuity is complex as they can be construed as negative *and* positive. For example, intimacy and subjugation both describe forms of being continuous, whereas distance and self-determination both describe forms of being discrete. The experience of feeling at 'home' provides an insightful microcosm illustrating connection versus separation. In a review exploring the experience of home, Haak and colleagues (Haak, Malmgren Fange, Iwarsson, & Dahlin-Ivanoff, 2011) describe the home as the hub of *both* autonomy and participation. Similarly, in a review exploring the meaning of home, Malony conceptualises home as a place where I am discrete, yet also continuous; it is a place of empowerment where I can do what I want and where I can find refuge, yet also an important source of connection (Molony, 2010).

The central value of connection resonates with the Kitzmüller and colleagues' exploration of loneliness in older adults (Kitzmüller, Clancy, Vaismoradi, Bondas, & Wegener, 2018). They also highlight a distinction between feeling lonely and being alone. They conceptualise a wall disconnecting older adults from the world; this disconnection is exacerbated by loss of loved ones, and also by social change that leaves people feeling isolated and abandoned. Their metaphor of being 'trapped in an empty waiting room' is

useful as a focus for health and social care as it creates the possibility of re-opening or keeping the door open. Our findings indicate that connection to the natural and global world can also make an important contribution to opening the door and retaining vitality into older adulthood. This can be particularly important where friends and loved ones are absent.

Our findings resonate with other QES exploring the experience of older (but not so old) adults which also highlight the high value placed on staying independent at all costs. Song and colleagues suggest that older people's definition of health hinged around independence (Song & Kong, 2015b). Abad-Corpa and colleagues (Abad-Corpa et al., 2010) highlight the tension between independence and dependence and the importance of integrating this into a new personal biography. Our findings demonstrate a desire to keep a tight hold of your reins to prevent others from taking control and show that this feeling was accompanied by powerful emotions. This emphasis on independence, self-determination and personal autonomy *at all costs* deserves attention. The Oxford English Dictionary defines *autonomy* as the 'liberty to follow one's will; control over one's own affairs; freedom from external influence, personal independence': *heteronomy* is the opposite of autonomy. The strong feelings associated with threatened autonomy may be grounded in enlightenment philosophies that underpin Western thinking. In particular, Immanuel Kant, who remains an influential Western philosopher, frames heteronomy as a compromise to personal freedom (Williams, 2008). This helps us to understand the strength of feeling when autonomy is threatened. It may be particularly true in a generation who have survived World Wars. However a contrasting view of heteronomy, articulated by Emmanuel Levinas, provides a useful frame. Unlike Kant, Levinas does not construe heteronomy as servitude. Levinas proposes that freedom is *contingent* upon heteronomy (Levinas, 1998); a life where we are free to make moral choices is only possible where we live connected to 'the other'. Connection therefore precedes self-determination as without it, there are no choices to make.

Our findings highlight the value of connection. We conceptualise connection as a series of concentric circles that cannot be divorced from the individual. Throughout life humans *are* dependent on each other, not only for biological and physiological needs and safety, but also for belonging, love, esteem, personal growth and fulfilment (Maslow, 1943). Register & Herman (M. Register & Herman, 2010; M. E. Register & Herman, 2006) explore the phenomenon of connection in adults over 65 and suggests that, ‘connectedness forms the basis for all human existence and . . . brings quality to life’. They propose facets of connection which resonates with ours (i) *biological connection* (with your own body); (ii) *connection to others* (living and deceased); (iii) *connection to society* (both locally and globally). (iv) *metaphysical connection* (with the universe) (v) *environmental connection* (with the natural world); (vi) *spiritual connection* (with the divine). Ebrahimi and colleagues also found that being involved in life, having human contact, being part of nature and the world, contributed to frail older adults’ perceptions of health (Ebrahimi et al., 2012).

Unlike, Register & Herman, we did not include *biological* connection: our sense of being diminished in very old adults hinged upon loss of *external* connection. Although our finding ‘I am diminished’ described an old and vulnerable body, there remained a sense that this body is still *my own*. In contrast, Clarke and Griffin describe older people with multiple chronic conditions in later life as ‘trapped inside this decaying body’, giving a sense that the body is no longer mine (Clarke & Griffin, 2008). Similarly, others have shown that adults’ with chronic musculoskeletal pain describe a disconnection between body and self (F Toye et al., 2013a). In this way, Drew Leder describes how being *ill* makes us suddenly aware of our own body; the body ‘*dys*-appears’ (Leder, 1990). Health presupposes that we remain silently connected to the body. Further studies might usefully explore the experience of biological connection in subgroups of older adults.

Our conceptual model highlights the paradox of time: ephemeral, yet interminable. Although time slips away, it also seems to stand still. This paradox is lived both in the moment and yet also transcending the moment through reminiscence. Living in the moment can mean filling time with routines, or it can mean remaining ever curious and engaging in lifelong learning. This finding has implications for living well across age groups and is pertinent for assessing quality of life. Our model also highlights the importance of reminiscence: it can allow us to transcend the moment and draw strength from adversity and prosperity. Duggleby and colleagues also show that transcending the moment and reaching inward to uplifting memories can provide strength (Duggleby et al., 2012). Ironically, it is through transcendence that we recognise both the infinite and the finite nature of existence and contemplate death. This resonates with Manning's conceptualization of *spirituality* as "a source of transcendence; [a] belief in something greater than themselves" (L. Manning, 2013). In this sense, spirituality need not hinge upon connection with the divine, but on a sense of being part of something greater, whatever form that might take. Manning suggests that spiritually could be a protective buffer against adversity, therefore contributing to accumulated resilience and well-being. However, it is worth considering that there are times where adversity might outweigh an individual's resilience, through no fault of their own.

Finally our model highlights social discourse on *successful* aging. We highlight the social expectation to age well: to have a good attitude, to lead a life of honour and to look after your own body. This resonates with other QES exploring the experience of aging (Klugar et al., 2016). Ebrahimi suggests that being happy, accepting change, thinking positively and feeling proud can underpin a sense of good health in frail older adults (Ebrahimi et al., 2012). However, these same adults experienced a sense of shame for not being unable to live up to the social expectations to age well (Ebrahimi et al., 2012). What if we do feel sad, or cannot accept, or feel low, or feel shame? "Blaming the flowers for

wilting” is a powerful metaphor used by Harris and colleagues to challenge the social discourse of successful aging (Harris et al., 2015). This discourse positions health in old age as a matter personal choice and takes the burden of responsibility away from society and places it on the individual. It fails to recognise the discrepancy of people’s experience throughout life. Rather, the discourse frames illness as a personal failure: “an outcome of irresponsible choice-making”. A more compassionate response might read: there but for the grace of God, go I (anon). Clarke and Griffin highlight the inevitability of the aging process (Clarke & Griffin, 2008): “Age cannot be repaired, cannot be altered. Age is coming”. At some point in our lives we will not be in a position to choose health, and this can cause strong feelings of guilt. Even at the transition into the end of life, Martz and Morse found that guilt underpinned the experience of older people and their families (Martz & Morse, 2016).

These findings have implications for health and social care as they can mean that people may not access the help that they need for fear of stigma. For example, Kharicha show that some will hide and endure loneliness (Kharicha, Iliffe, Davies, Walters, & Manthorpe, 2018). It is therefore important to reflect on the discourse of successful aging and consider its challenges. For example, how do we balance expectations to adapt and accept with the expectation that you should not give in; how do you decide when to look after your own aging body and when to seek help: how do you remain positive in the face of overwhelming losses? These are some of the challenges of very old age.

It is likely that men and women experience aging differently. Gender refers to the socially prescribed and experienced dimensions of femaleness or maleness, and theories of gender provide a backdrop to understanding differential responses to the body. Aléx and colleagues describe women living a life in the shadow of significant men (fathers, brothers, husbands)(Alex et al., 2006). They also highlight gendered talk, with men focusing on strength, hard work, stubbornness, and women focusing on fulfilling their caring roles at

home (Al  x & Lundman, 2011). Similarly, Hedberg and colleagues uniquely explore the experience of men (Pia Hedberg et al., 2013) and women (P. Hedberg et al., 2009). Further primary studies might usefully explore differences in specific samples related to gender, age, socio-economics and other factors. Our findings were comparable across older men and women and could provide a useful base for comparison. In our scoping review, we identified more than 100 existing QES that explored the experience of adults over the age of 60, including dementia. A review of existing QES would help us to build on existing research and to explore the potential impact of qualitative research findings for policy and practice.

We used the GRADE-CERQual framework (Lewin et al., 2018) which aims to rate confidence in findings. However, there is no agreed method for quality appraisal and a significant proportion of QES reviewers choose not to appraise (Dixon-Woods, Sutton, et al., 2007; F Toye et al., 2013b). Although QES reviewers will often quality appraise, there tends to be low agreement (Dixon-Woods, Sutton, et al., 2007) and little is known about the impact of appraisal on QES findings (Campbell et al., 2011; Hannes & Macaitis, 2012). We suggest that it is important to determine whether a study is *good enough* (F Toye et al., 2013b). After this, studies with robust ideas will influence the analysis and weaker studies will “do no harm” (Campbell et al., 2003). Future studies might address how we can be more discerning about the value of particular studies (F. Toye, Seers, & Barker, 2017). GRADE-CERQual considers adequacy (weight) and coherence (consistency) of data as integral to confidence. However, how do we know *what* adequate is? We indicate the number of studies supporting each finding as an indicator of both coherence and adequacy as this reflects the spread and depth of data. This is a large QES and we rated our confidence as high when it was supported by at least half of the studies. However, although we agree that confidence can grow when you incorporate a large number of studies, ‘a unique idea can exert a significant pull’ (F. Toye et al., 2017). The *richness* of data contributing to a finding may make a weightier

contribution to idea development and reviewers may wish to consider whether an exhaustive search of the literature is necessary (F Toye et al., 2014). Some QES reviewers suggest that you could stop searching when additional data adds no more insight (Charmaz, 2006). It may be that continuing to search for studies beyond the point of theoretical saturation is not useful. Three studies identified post hoc did not highlight any additional concepts, suggesting theoretical saturation in this QES. Further studies might explore the added value of different search strategies. The potential number of studies identified for a QES can reach several thousand and research time is not necessarily well spent verifying screening. GRADE-CERQual also considers relevance to be a facet of confidence in review findings: however you could argue that all qualitative studies aim to provide a partial or indirect window into lived experience; and this is its strength rather than its weakness.

This is the first QES to conceptualise the experience of being extremely old. Our study challenged the stereotypes of old age and has the potential to influence people's actions and perspectives towards aging. This resonates with one of the strategic objectives of the WHO Global Strategy and Action Plan on Aging and which aims to 'combat ageism and transform understanding of aging and health' (World-Health-Organization, 2017). However, at the same time we highlight discrepancies in experience that should underpin health and social care policy. Our conceptual model helps us to understand the phenomenon of connection and to consider its impact upon the quality of older adulthood lives. Our model challenges clinical educators, clinicians, policy makers and wider society to incorporate innovative ways to support connection, in all of its spheres, into peoples' lives. It also encourages us to reflect upon the influence of philosophies that might undermine the value of connection. Future studies to explore the experience of connection and its impact on quality of life into older adulthood would be useful. Healthcare interventions which focus on connection and living *selectively* in the moment may improve the quality of life into older adulthood.

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