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Title: Aging well with psychosis

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Abstract

Background and Objectives: Despite the unique challenges faced by people living with a severe mental illness, little work has been done to understand how these populations can age well. This study therefore aimed to explore the views of mid to older aged adults living with a psychosis on what it means to age well, and how they might be supported in this endeavor.

Research Design and Methods: Semi-structured interviews were conducted with sixteen individuals (age 50-74 years) diagnosed with psychosis-related disorders (e.g. schizophrenia). Inductive thematic analysis was used to analyze the data.

Results: Four themes were identified: (i) *Engagement with Life* - referring to participating in, and maintaining, activities that bring satisfaction and value; (ii) *Attitude to Life and Aging* - referring to a positive attitude and outlook, and accepting aging-related challenges; (iii) *Health and Wellbeing* - relating to keeping as physically and mentally fit as possible and (iv) *Social Connections* - referring to both personal and professional relationships, and feeling heard and understood by others.

Discussion and Implications: Whilst there were clear parallels between these results and those reported from other populations, participants aging with a psychosis revealed challenges, perceptions, and nuances that were unique to their situation. The importance of relationships with professionals, developing a mastery over their mental health difficulties, and the continued impact of stigma on aging well were highlighted. This suggests that approaches that target external societal factors, as well as therapeutic interventions focused on the individual, may help this population to age well.

Key Words: Psychosis; Schizophrenia; Successful Aging; Qualitative; Psychosocial

Background and Objectives

Psychosis is characterized by hallucinations and delusions, and can cause distress and disability for the person and their family (Public Health England, 2016). Previous work has shown that social support and active participation to create a meaningful life are important for living well with psychosis (Pitt, Kilbride, Nothard, Welford & Morrison, 2007). However, less is known about what it means for this population to *age well*. Given that the proportion of adults over 55 years is likely to double in the next 20 years (Cohen et al., 2008), it is important to understand how to support older people with psychosis to ensure they have opportunity to age well. This is particularly the case when considered in the light of social gerontological theories of cumulative disadvantage (Dannefer, 2003), which would predict that relative disadvantages related to poor mental health, and its associated consequences, present in early life are likely to increase over the life course.

One of the most prominent models of successful aging for the general population is the three-part biomedical model (Rowe & Kahn, 1997), which operationalizes successful aging as: the avoidance of disease and disability; the maintenance of cognitive and physical functioning; and continuation with social engagement. However, this model limits the number of older adults who are defined as aging well to those with near-perfect health (McLaughlin, Connell, Heeringa, Li, & Roberts, 2010). People living with chronic mental health conditions do not meet these criteria, suggesting that they do not have the potential to age successfully. Whilst a more recent update to the model highlighted the need to also consider societal factors (such as social policies, organizational structures, and societal norms relating to roles and activities undertaken across the lifespan) that influence an individual's ability to age successfully (Rowe & Kahn, 2015), this model still fails to consider how one can age successfully in the presence of disabilities or care needs (Tesch-Römer & Wahl, 2017).

Other models of successful aging have focused on the perspective of lay people, as opposed to those of researchers (Cosco, Prina, Perales, Stephan, & Brayne, 2013), on the basis that they can add insights that might otherwise be overlooked (Martinson & Berridge, 2015). Indeed, a review of studies exploring lay person perspectives found a more multi-faceted concept of successful aging than proposed by Rowe and Kahn's model that incorporates a broader range of psychosocial (e.g. acceptance and engagement) and external factors (e.g. finances) (Cosco et al., 2013). However, there are still 'missing voices' within the literature of lay perspectives of successful aging (Martinson & Berridge, 2015, p.60), one of which is people with severe mental health conditions, such as psychosis-related disorders like schizophrenia. This is particularly important given that older adults with these conditions have significantly lower quality of life compared to age-matched peers (Folsom et al., 2009), and lower life expectancies than the general population (Laursen, Nordentoft, & Mortensen, 2014), and that symptoms of psychosis have been linked with increased risks of dementia and cognitive decline in later life (Köhler et al., 2013). Older adults with schizophrenia are also less likely than those without schizophrenia to meet the criteria of successful aging set out in Rowe and Khan's original model (Ibrahim, Cohen & Ramirez, 2010). Together with the fact that these adults are amongst the least likely to access services (Wuthrich & Frei, 2015), the importance of understanding how this population defines successful aging is a vital step in ensuring that this population group receives appropriate support.

The aim of the current study was therefore to address this gap by performing qualitative analysis of interview data to explore what aging well means to mid to older age adults who have lived with psychosis throughout their lives, and how this can be better supported. The more moderate concept of 'aging well' was used to frame this study in line with arguments

that the term ‘successful aging’ promotes a dichotomous perspective of aging that might be insufficiently inclusive (Peterson & Martin, 2015), and therefore less suited to a population defined by the presence of a mental health disorder.

Research Design and Methods

Participants

Inclusion criteria were: (i) aged 50 years and above; (ii) diagnosis of schizophrenia or psychosis-related disorder that had been received prior to the age of 40, and had been confirmed by a medical professional; (iii) sufficient cognitive capacity and language proficiency to provide informed consent and take part in interviews in English. Purposive sampling was used to recruit people across a range of age brackets, genders, ethnicities, number of hospitalizations, and levels of carer dependency.

Sixteen participants were recruited (Table 1). Nine of these participants were recruited from community mental health teams (CMHTs). For these participants, clinicians from the CMHT identified and contacted potential participants to get their consent to be contacted by the first author. If they consented, then the first author contacted them to discuss the study, and provide a copy of the information sheet. Five participants were recruited from a database of participants who had taken part in a previous interview study about barriers to accessing psychological support that was conducted by the second and fourth authors (Berry et al., 2020), and had agreed to be contacted about future studies. These participants were contacted by the first author, who had had no involvement in the previous study, and invited to take part. The remaining two participants were recruited via self-referral from a local support group following a presentation, delivered by the first author, which provided details about the

research during a meeting. Nearly all participants (n= 15) were currently receiving support from a CMHT.

<Insert Table 1>

Ethical approval

Ethical approval was granted by the Greater Manchester East Research Ethics Committee (ref: 219388).

Procedure

All participants provided written informed consent. Interviews were conducted by the first author using a flexible semi-structured topic guide, which provided a consistent framework across interviews, whilst allowing for adaptation to discuss unexpected topics and avenues of questioning. The interviews elicited participants' views, opinions, and experiences about aging well/successfully, and how this has been supported, or not. For example, participants were asked to describe people who they did or did not consider to be aging well/successfully, and to discuss the influence of services and other people on their own ability to age well/successfully. The terms 'aging well' and 'aging successfully' were used interchangeably with the term during the interviews, allowing participants to consider both conceptualizations when responding to the questions. The interviews lasted from 20-90 minutes, and had an average duration of 42 minutes.

Data analysis

Verbatim transcripts of the interviews were analyzed using an inductive thematic analysis, following the method outlined by Braun and Clarke (2006). A realist approach, which focusses on the 'experiences, meanings and the reality of the participants' (Braun & Clarke,

2005, p.81) was taken to the analysis. For this, after a period of data familiarization, relevant extracts from each interview were identified, copied into an Excel worksheet, and given a descriptive code by the first author. An open coding system was used, in which the meaning of each extract in relation to the research question was captured using a short descriptive phrase, including an indication of whether it related to aging well or not. Examples of codes assigned to specific extracts are available as supplementary material (Appendix 1). Extracts with related codes were initially grouped by the first author to form preliminary themes. These grouping were made on the basis of a shared organizational concept, irrespective of whether or not the constituent codes reflected the same *views* about the underlying topic(s). Preliminary themes were then reviewed, and iteratively refined, through discussion with all authors.

Results

Four themes and eight sub-themes were identified (Table 2.). Additional quotes to support each theme are available as supplementary material (Appendix 2). Pseudonyms indicating the gender of the participant have been provided for all quotes.

<Insert Table 2>

Theme 1: Engagement with Life.

Keeping active

Participants felt that keeping active is an important element to aging well. Activity types varied across participants, and included organized activities and courses, mental health groups, and physical activities, such as rambling. Reported reasons for engaging with activities included: keeping busy; enjoyment and satisfaction; bringing meaning into life; and maintaining “social connection with people” (‘Wilfred’, age 70-75). Some participants

particularly valued mental health group activities because they were a space in which they could meet other people “with the same problems” (‘Carol’, age 50-55) as them.

Some people spoke about the barriers to accessing activities, describing either difficulties getting out of the house or struggling to engage with others. For example, ‘Colin’ (aged 65-70) said: “[Community groups] caused me too much stress relating to people you see. I’ve always had difficulties with personal relationships: it’s one thing I would like to improve on [to be aging well]”.

In comparison to organized activities, several participants placed more significance on “just being able to cope with things normally” (‘William’, age 70-75), and being able to continue to perform everyday tasks, as an indicator of aging well:

On my behalf it would mean me, erm, being able to function from day one to day two, easily wake up in the morning, I can maybe have a shower, erm, have my breakfast, er, maybe iron me clothes, I have me clothes clean, get clean clothes worn, so that I’m not wearing dirty clothes, and, erm, maybe taking care of the flat sometimes.

(‘Paul’, age 55-60).

Having a valued role and purpose

Some of the younger participants stated that having a job, and support to gain employment, was important to aging well. For example, ‘Yvonne’ (age 50-55) reported “I think I’m doing better than most in terms of... I’m still studying. I’m still interested, I still love my job, I’m still very interested in my job”. Similarly, others, like ‘Wilfred’ (age 70-75), suggested having had “a successful life, past life”), such as a past career and job satisfaction, were key to aging well.

Many participants reported being unable to pursue or continue in careers because of their mental health difficulties. Instead, they had pursued other roles that gave their life purpose, such as voluntary jobs, or had gained satisfaction through being able to “pass on knowledge” to others (‘David’, age 60-65), or by helping others:

Hopefully they [the participant’s future grandchildren] won't be mentally ill, and if they are, they'll know how to deal with it because I know so much. So I see myself as still having a valued role I suppose in supporting them and loving them and caring for them and looking after them my whole life really when I'm a Grandmother myself hopefully (‘Yvonne’, age 50-55).

Others described the dilemma of wanting more from life to feel that they were aging well, but noted that they “don't know how to get something more out of life” (‘Mary’ age 70-75).

Theme 2: Attitude to Life and Aging

Having a positive attitude

Engaging with life necessitated a positive attitude to living and aging well. For some this was about making the most out of life, or being grateful for the things they had. For instance, ‘Paul’ (age 55-60) stated: “I’ve got to be thankful for certain things that ...: One, I’ve got me own flat. Two, I’m not in hospital. And three, I’ve got me health, as, as bleak as what it is, because there’s some people that ... ain’t got those things”.

Others described aging well as being able to carry on despite difficulties: “Well I don't do so well, and there are other people like me that don't do so well. But it's not about whether you do well or not; it's about getting on with your life to continue to progress.” (‘Ben’, age 55-60).

Linked to having a positive attitude was the idea that aging well was about being content with yourself or life; an inner sense of satisfaction and success: “You’re not out there trying to be a go getter, ‘cos it’s actually internal: you have to feel good, not what society calls it. I feel settled in myself, and I’m successful, and that’s good, and that feels nice” (‘Beverley’, age 50-55).

Some participants described that thinking about the future was not helpful, and suggested living more in the moment or taking ‘each day as it comes’ (‘Carol’, age 50-55) was more important to aging well.

Some people also stated that aging well was being able to live life how *they* want: to “Have it all on my terms and not what people say” (‘Paul’, age 55-60). However, many felt that this was restricted because of the ‘element of dependency’ that comes ‘with the illness’ that would be ‘good to try and move away from’ (‘William’, age 70-75). This dependency often meant that aspects of participants’ lives were heavily influenced by other people: “It’s very difficult, when they are so powerful, to have your own life and lead it how you want to lead it. My Psychiatrist sees me every six months anyway and wants to boss me around, which I don’t like. I’m left with no alternative” (‘Mary’, age 70-75).

Accepting change and circumstance

Participants reflected on what they may or may not have achieved in their life, and how their mental health may have affected this and, in turn, their ability to age well. Some spoke about coming to terms with, or reaching a level of acceptance about, their experiences, which was a key element to them aging well:

[What does aging well mean?] I think about what your life's brought to you, and coming to terms with that. And it's a kind of grieving process for what you may have had, when you've been mentally ill. And if I hadn't have been mentally ill, what could I have achieved? ('Yvonne', age 50-55).

Others reflected that one's life satisfaction was inextricably linked to comparing themselves to people without mental health difficulties, which highlighted missed opportunities:

I'm lucky I have enough money to have my hair done if I want but it's very much scraping the barrel when my sister has the best meat and everything that opens and shuts. And it's difficult not to be jealous of how this has brought me so low. She owns a house, I have a rented accommodation ('Mary', age 70-75).

Whilst many people described the importance of physical appearance, and felt that looking good, or younger than your age, was an indicator of aging well, many also posited that an acceptance of physical changes was important. Not accepting these changes, or having a preoccupation with trying to be younger or more youthful, was detrimental to aging well: “[What does not aging well mean?] ‘Er, I think you panic about how you look. You panic how you look, and you try all sorts of things to make yourself younger...’” ('Beverley', age 50-55).

Theme 3: Health and Wellbeing

Maintaining physical health

Most participants made reference to physical health being part of aging well. Despite not always being in good health, the majority of people spoke about having good fitness, and remaining physically able and active: “I think I’m aging well for me age because I’m still fairly active, you know. I don’t get too tired from walking or anything like that” (‘Colin’, age 65-70).

Some participants felt that aging well in regards to physical wellbeing involved caring about yourself enough to *want* to maintain your health. For these people it seemed that allowing your health to deteriorate by lack of care, and to ‘let yourself go’ (‘Tony’, age 60-65), appeared to signify not aging well.

Similarly, other people described themselves or others adjusting to their physical health problems so that they could continue to age well with these difficulties:

I think of my Aunt who's a very successful person, who into her 86, 87. She had a leg removed and she came to terms with that and she got herself a scooter, she got herself a dog, she was round the field round the back of the house four times a day you know (‘Yvonne’, age 50-55).

Mastering mental health

Participants also placed mental wellness as a significant factor in aging well. There was an apparent paradox in that a reasonable proportion of participants reported not feeling able to describe someone with mental health issues as aging well, yet many described themselves as aging well. For instance, one participant ('Yvonne', age 50-55) stated that "a vast majority [of people with a mental health problem] don't really [age well]". However she saw herself as an exception to this: "But I think I'm not doing too badly compared to my peers... I'm not your typical nutty person!"

People reported a variety of ways of coping, such as talking to other people, psychotherapy, learning different techniques, and making sure they have good quality sleep. For many, there was a continuous effort in managing their mental health to ensure stability. However, they also spoke about feeling more adept at coping with their mental health as they have aged, learning from their past experiences: "...there's been so much inner growth that I wouldn't really call myself ill really now...I seem to be able to manage a lot better than I used to" ('William' age 70-75).

Nonetheless, the presence of relapsing mental health problems throughout people's lives created uncertainty. The possibility of relapse meant that valued areas of their lives felt jeopardized. This was not just their mental health, but also the security that they had built:

I have lost my flat and all my property at a certain point in time... in the past but not in the recent part. And when that happened I felt that I can't let that happen again, so I

have to look after my mental health, because once my mental health goes, everything, everything in here is at jeopardy straight away ('Paul', aged 55-60).

A subset of participants felt that their illness had progressed as they got older. These participants often described the presence of symptoms impeding aging well: "I find it very, very hard, and I keep very much to myself, because I'm getting older. When I was younger, I could cope with it much better than what I can do it now" ('David', age 60-65).

Some participants emphasized the desire for an absence of any mental health symptoms to categorize themselves as aging well: "I think if I didn't have the voices. It [aging more successfully] would be to get rid of the voices and to carry on living well without the voices" ('Carol', age 50-55).

Alongside specific mental health issues, the concept of continued cognitive integrity was also discussed as being important to aging well. In line with this, participants spoke about "*keeping the mind active*" ('Colin', age 65-70) as a means of staving off cognitive deterioration. Some individuals also expressed being "very worried about dementia, things like that" ('David', age 60-65), which seemed, for them, to be a signifier of unsuccessful aging.

Nearly all participants were still involved with mental health services. For many, they felt this support was crucial in maintaining their mental health: "I suppose it's getting a lot of support from the nurses psychiatric nurses... Some of the nurses used to take me out to various places, you know, and that's helped me a lot to keep me young, to age well" ('Colin', age 65-70).

Many described that having this continued support in the background, or just in case of crisis, allowed them to continue to age well: “If I need to get in touch with anybody, I get in touch with the crisis team. So I've always got a backup plan when I'm not well” (‘Carol’, female age 50-55). However, for some, this was also a reminder that they would potentially always need a certain level of additional support: “And part of me is very, very sad sometimes, that I need this help. But I need their care to get through the illness” (‘Beverley’, age 50-55).

For many, medication was seen as a positive way of managing their mental health and providing stability to age well: “It just relaxes me, the injection” (‘Stewart’, age 55-60). Yet, for others, whilst there was a degree of acceptance about needing to be on some form of medication, this was not welcomed. This subset of participants described that anti-psychotic medications had been detrimental to the aging process: “I mean, mental health stops you aging properly anyway; that's the drugs and the psychiatric pills and what have you make you ten times worse in my opinion” (‘Mary’, age 70-75).

Theme 4: Social Connections

Connecting with others

Participants placed significance on the role of interpersonal relationships in the development and maintenance of successful aging: “[What does aging well mean to you?] ...being surrounded with a loving family and friends, and you're happy in relationships, and you do the things you'd like to do between you and help each other to get by the best way you can.” (‘Wilfred’, age 70-75).

These relationships were important, not least because of the support and understanding that many of the participants' families gave in regards to their mental health: "[How have family helped you to age well?] Give me plenty of support, you know, and understanding.

Understanding the illness" ('Colin', age 65-70).

For some, family was their only source of social connection: "I haven't got many friends really, being indoors all the time. I've only got me family, you know" ('Moira', age 60-65).

It seemed that, whilst those who had families often reported still having, or looking forward to having, a valued role as a grandparent, the absence of this opportunity for others was a reminder of a life they should or could have had, if their mental health difficulties had been different: "I'm single. I haven't ever been married. I've never had a child and you have to cope with your brother and sister having all the normal side life, and you're stuck on your own with nothing." ('Mary', age 70-75).

Many participants spoke about their friendships, and the importance of having a support network: "...my friend[s], they keep a special eye on me, and I keep a special eye on them, you know, we got a, we got a good system going, and if one of us drops or one of us, goes down, we all pick him up" ('David', age 60-65).

In contrast, other participants spoke about a real struggle to form relationships throughout their lives, and about how being 'inept' about 'social things' was part of 'not being well' ('Tony', age 60-65). These participants reflected that social isolation and loneliness was a reason for not considering themselves to be aging as well: "I'm being kept isolated. I'd like to be able to welcome people into me home and to be able to share what things I've got. I mean

you could have a mansion and if you're the only person who goes in that mansion it's a very lonely spot." ('Tony', age 60-65).

All participants spoke about the importance of their relationships with mental health professionals for aging well. For many, professionals had been a part of their lives for several years. In the absence of other relationships, these professional interactions provided people with much needed companionship and friendship: "I mean they've [mental health professionals] provided me with, I think, very often I felt very isolated and they, they used to come and give me company you know, a bit of moral support that sort of thing" ('William', age 70-75).

Good relationships with staff facilitated trust and honesty, and helped people to age well:

[My clinician is] just a really nice character. Obviously when he first started coming seeing me I weren't like I am now. So he's seen part of the worst. I kept doing things thinking I got to do this so [my clinician] will be proud when he gets here. It's mad, innit? ('Patrick', age 60-65).

In contrast, difficult relationships with staff led to dissatisfaction with the care people received, and an increase in masking emotional distress and symptoms for fear of mistreatment or unwanted repercussions. For these people, not having positive relationships with staff prevented them from aging well:

[describing how staff have been unhelpful to aging well] Well drugs number one. Not being able to talk to somebody that knows, who knows what to do is two. Having

very little time to talk over anything with him is three. Thinking he knows what he's talking about is four. And when there is nobody else to fall back on he thinks himself terribly clever. He doesn't help aging well at all. He's a stumbling block as far as I'm concerned ('Mary', age 70-75).

Being heard and understood

Many participants described situations in which they had not been listened to, and the effect this has had on their sense of aging well: "Well they've [services] not listened to me. For thirty years. And they still treated me like a paranoid schizophrenic when it was emotional trauma I was going through every day of my life." ('Tony', age 60-65).

For this group of people, good relationships with friends and family, and with professionals, allowed them to be listened to, and also understood in terms of their experiences, rather than just their diagnostic label. Nearly all participants talked about how others trying to "be understanding and listen to them" ('Paul', age 55-60) was one of the main ways that other people could facilitate aging well.

The majority of participants spoke about how stigma about mental health had affected their lives. Some of the older participants also reflected on how this stigma had affected their ability to age well: "Oh, yes, made it more difficult [to age well], and people, they tend to be frightened of me, of what I don't know ... probably 'cos they, they've heard that mental illness people, they come out with knives and all that." ('David', age 60-65).

Some participants explained the additional impact of this stigma in a society that doesn't value older generations: "It's been definitely the stigma of double whammy of the aging and

the psychosis is very hard for them to bear. I think for older people in particular the stigma is greater isn't it" ('Yvonne', age 50-55).

Discussion and Implications

This study aimed to explore the meaning of aging well to middle and older age community dwelling adults with psychosis. The first theme, *Engagement with Life*, described how participating with activities that bring satisfaction, meaning, and value to life helped participants to age well. The second theme, *Attitude to Life and Aging*, outlined the importance of maintaining a positive attitude, to ‘carry on’, and reach a level of acceptance about what life and age have brought. The third theme described how participants considered *Health and Wellbeing* to be a key component of aging well. This encompassed factors in regards to physical, mental, and cognitive health, as well as having a sense of security with life. The final theme illustrated how *Social Connections* helped participants to age well. This not only involved participants’ personal relationships with family and friends, but also their relationships with staff. These findings help to address previous critiques that successful aging models have suffered from a lack of diversity in terms of the people represented (Martinson & Berridge, 2015), and/or have failed to consider how people can age successfully when living with disability or having care needs (Tesch-Römer & Wahl, 2017).

Some findings are consistent with literature on successful aging in other populations (Dupuis & Alzheimer, 2008; Rowe & Kahn, 1997; Rowe & Kahn, 2015). For instance, participants described the importance of engaging with life to bring enjoyment and value to help them to age well. This involved participation in leisure type activities, as well as being able to manage everyday tasks independently. A longitudinal study of successful aging has previously shown that these types of activities are related to greater happiness and function in older age, although more everyday activities were only associated with happiness (Menec, 2003). In the current study, these activities helped to bring meaning, enjoyment, and a sense of social connection into people’s lives, which appeared to facilitate a sense of aging well,

particularly the ability to continue to have a valued role into their older age, and/or when they were unable to partake in paid employment. A unique factor in this sample of people with psychosis was meeting other people with similar difficulties, who understood and accepted their mental health difficulties; perhaps because being around others who understand and accept one's difficulties may promote a sense of belonging, which is a key domain of quality of life (Renwick & Brown, 1996). This is one of several findings from this work that highlights the importance that external factors (in this case community services for people with specific mental health difficulties) can have in supporting participants with psychosis to age well. This is in line with arguments that successful aging discourses should consider social components and determinants of 'success' rather than focusing solely on personal responsibilities (Fletcher, 2020).

Participants also spoke about the importance of accepting and adjusting to difficulties. Whilst participants spoke about how age or their mental health had impacted their ability to engage in life the same as they did before, which affected their sense of aging well, many spoke about the value of accepting and adjusting to these changes. Similar findings have been described in a study which examined successful aging in people with chronic health conditions (Romo et al., 2013). Taken together, such findings suggest that that, when people cannot enter older age free of 'chronic conditions', their attitude can at least, in part, still enable them to age well.

As in previous research, participants described how the maintenance of physical and psychological wellbeing was important for aging well (Bowling & Dieppe, 2005; Cosco et al., 2013). However, aging with a psychosis led to differences in how this was achieved. For example, participants in the current study more commonly described participating in health

promoting behaviors and keeping physically fit, rather than freedom from physical health issues, as indicators of aging well. In line with the higher rate of co-morbidities seen in older adults of this population (Smith, Langan, McLean, Guthrie, & Mercer, 2013), many described that physical health difficulties were an aspect of their aging which was less successful.

One of the greatest disparities between this study and previous research related to the domain of mental health. As in other studies (Cosco et al., 2013), participants made reference to maintaining good mental health to qualify as aging well. However, in this population, aging well was conceptualized as a ‘mastery’ over mental health problems rather than a freedom from them. Nonetheless, the potential for relapse was also a reality. In the face of continued difficulties with their mental health, some participants still considered themselves to be aging well, and described utilizing the support of services, social support, and their own positive attitude and acceptance of these difficulties to sustain this. However, others were unable to reconcile their circumstances and did not consider themselves to be aging well. The pursuit of mental stability was not just a priority for people’s psychological wellbeing, as their financial and environmental security often depended on their ability to remain ‘well’. This ultimately left some participants with a fragile sense of security, which could be considered a state of precarity (Grenier et al., 2020). In line with previous studies on lay perceptions of aging well in other populations (Cosco et al., 2013), this again highlights a role of external factors (such as stable benefits and secure housing) as being important to aging well in this group.

For this group, positive relationships and social networks were integral parts of aging well. This too has been described across the literature in other populations (Bowling & Dieppe, 2005; Rowe & Kahn, 1997; Rowe & Kahn, 2015), reflecting the universality of this domain

of successful aging. Indeed, social networks and support have been shown to be strong predictors of life satisfaction in older age (Gow et al., 2007), and are associated with fewer hospitalizations and better functioning (Siette, Gulea, & Priebe, 2015). However, it is also known that social connections can be difficult for a person to access once they have been socially isolated for a long time (Machielse & Duyndam, 2020). This is particularly important for this group given that, in line with the known difficulties that psychosis can have on the ability to form stable relationships with others (Degnan et al., 2018; Palmier-Claus et al., 2020), many participants spoke about having a lack of friendships or families of their own, and of periods of social isolation.

Perhaps, in part, because of these difficulties with social relationships, one novel aspect of this theme was the importance placed on professional relationships for aging well; thus highlighting another role of external factors required to support this group to age well. In line with existing knowledge about the importance of the therapeutic relationship to mental health outcomes (Ackerman & Hilsenroth, 2003; Hartley et al. 2020), clinicians should be aware of the role that their relationships with clients can have in facilitating positive aging, especially given that several participants reported the negative impact that poor experiences with mental health staff had had on them. Good relationships with staff, family, and friends also allowed people to be heard and understood, which many cited as the best way to support people with aging well. This was seen as particularly important given the ‘double whammy’ of stigma relating to mental health and ageism (Graham et al., 2003) that is associated with growing older with a mental health problem.

The literature from the adult population concerning living with psychosis also provides an interesting comparison to the current study’s findings. For example, studies exploring service

user perspectives have emphasized the roles of ‘rebuilding life’, increasing social support, and active participation to create a meaningful life (Pitt et al., 2007). This could suggest the importance of these factors on wellbeing for people with psychosis throughout the life course as well as for aging. Stigma is an undeniable factor that affects people with psychosis irrespective of age (Burke, Wood, Zabel, Clarke & Morrison, 2016). In younger adult populations, the literature highlights how motivation for societal change and changing people’s perspectives on mental health can be a key part of people’s recovery (Pitt et al., 2007). For the current group of older adults, however, continued stigma appeared to be a hindrance to aging well, not least because they also had to contend with ageism as they have grown older. As such, they spoke more passively about dealing with stigma rather than a drive to instigate change. This may, in part, reflect a generational difference as, arguably, in today’s society there is increasing awareness and acceptance of mental health difficulties (TNS BMRB, 2014). Nonetheless, it also highlights another way in which external factors can influence an individual’s ability to age well with psychosis.

Previous work on living well with psychosis has also highlighted the important roles of learning to control symptoms of psychosis, or accepting that mental health difficulties are part of the whole person (Pitt et al, 2007; Law & Morrison, 2014). This supports the finding in the current study that participants saw their sense of mastery as having developed over many years. Additionally, for participants in this study, acceptance appeared to be a much broader concept, which reflected coming to terms with the experiences they had across their lifetime, both in regards to mental health and the aging process.

Clinical and Research Implications

These findings have important clinical implications, especially in helping service users to access support that may help them to age well. One key barrier to aging well reported in the study related to participants' particular difficulties in developing and maintaining social relationships. Interventions that seek to ameliorate these difficulties in social functioning could therefore promote successful aging in this population. One example of this is the integrated cognitive behavioral therapy and social skills training intervention that has been shown to be effective in improving social functioning in older people with severe mental illness (Smart et al., 2020).

The study also highlighted how acceptance of one's circumstances has an important role in aging well. Being unable to accept one's circumstances is therefore likely to be a barrier to aging well. One possible solution for this is the use of Acceptance and Commitment Therapy (ACT), which has as a core message: to accept what is out of your control, and commit to action that improves and enriches your life (Hayes, Strosahl, & Wilson, 2011). ACT has been successfully used with younger adults with schizophrenia (Johns et al., 2016). Future research into how ACT could be adapted for older adults with psychosis may help to facilitate a positive attitude and acceptance both in regards to aging and mental health difficulties.

The findings of this study also suggest that difficulties in looking after one's physical health would present barriers to aging well. Interventions that support older people to look after their physical health could therefore be of benefit to this group. The U.S 'Helping Older People Experience Success' (HOPES) study found that a multi-component skills training group that combined psychiatric and physical health self-management training (TNS BMRB et al., 2014) led to greater acquisition of preventive healthcare. This suggests that the

inclusion of this type of social skills and education in treatment plans with middle and older clients with psychosis could help them to age well.

Another barrier to aging well highlighted in this study was the ongoing impact of stigma and negative societal attitudes to both aging and people with mental health problems. This reflects an apparent societal expectation that people with mental health problems do not age well, despite this not necessarily being the perception of those with such difficulties. Given the impact that staff and service user attitudes can have on the care and support that older people with psychosis receive (Berry et al., 2020), interventions that challenge staff attitudes, as well as the internalized stigma that people with psychosis hold about themselves, could be beneficial in enabling this group to age well

Study limitations

Whilst there was diversity in terms of participant age, education, and social background, participants were recruited from one area of England, and the majority of the sample were ethnically White British. Therefore the findings may not be transferable to other ethnic groups. It was also not possible to recruit any participants in an older age bracket (75 years and over), which means that the voices of the oldest older adults are not heard. However, the current findings still provide valuable knowledge about the perceptions of aging well in a middle-aged and younger old sample, which is particularly relevant given the lower life expectancies of older adults with psychosis (Laursen et al., 2014). Finally, it is important to note that 15 of the 16 participants in this study were receiving support from a community mental health team. As such, the findings from this study may not reflect the views and experiences of people living with psychosis who are not receiving this support. This is particularly important given the high value that many participants in this study placed on

external support for helping them to age well, as well as the fact that there are known differences in the demographic profiles between those who are and are not receiving such support (O'Brien, Fahmy & Singh, 2009).

Conclusions

Some older adults who experience psychosis can still consider themselves to be 'aging well'. In contrast to the model proposed by Rowe and Kahn (1997, 2015), key factors that support aging well include: engaging with valued activities, developing a sense of acceptance, managing symptoms and physical health, and maintaining social connections with other people. Compared with previous work examining lay perceptions of successful aging, individuals with psychosis place particular importance on relationships with professionals, and developing a mastery over their mental health difficulties. They also highlight the impact of stigma on aging well. Importantly, the study has given a voice within the literature to those who often are not afforded this opportunity. It has also revealed how strategies for supporting people with psychosis to age well need to focus on external/societal factors, such as providing stable benefits and housing, fostering supportive relationships with staff, and reducing societal levels of stigma towards this group, as well as those that target the individual.

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Table 1. Participant demographics

Demographics (n=16)	Total
Age, mean (range, SD) years	61 (50-74, 8.32)
Gender, (n, %)	
Male	9 (56%)
Female	7 (44%)
Ethnicity, (n,%)	
White British	15 (94%)
Black British	1 (6%)
Diagnosis, (n, %)	
Schizophrenia	13 (81%)
Schizoaffective	1 (6%)
Psychosis NOS ^b	2 (13%)
Age of onset, mean (range, SD)	22 (11-30, 4.92)
No. hospitalizations, mean (range, SD)	7 (1-20, 6.14)
Education (highest level), (n,%)	
Secondary	7 (44%)
A-Level	2 (13%)
College	4 (25%)
Undergraduate degree	2 (13%)
Postgraduate degree	1 (6%)
Marital status, (n,%)	
Single	7 (44%)
Married	3(19%)
Common Law Partner	2(13%)
Divorced	4 (25%)
Received psychotherapy, (n,%)	
Yes	12 (75%)
No	4 (25%)
Psychiatric Medication ^a , (n,%)	
Atypical antipsychotic	12 (75%)
Clozapine	5 (31%)
Typical antipsychotic	5 (31%)
Anti-depressants	6 (38%)
Anxiolytics	5 (31%)

Note: ^a % values do not add up to 100 as some participants were taking more than one medication, ^bPsychosis not otherwise specified

Table 2. Main themes and sub themes

Main theme	Sub-theme
Engagement with Life	Keeping active Having valued role and purpose
Attitude to Life and Aging	Having a positive attitude Accepting change and circumstance
Health and Wellbeing	Maintaining physical health Mastering mental health
Social Connections	Connecting with others Being heard and understood

Supplementary Material

Appendix 1: Examples of descriptive open codes assigned to relevant extracts, and the final theme that they contributed to.

Extract	Code	Final theme /subtheme
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‘Keep ‘em um busy: a lot of it is boredom isn't?’ (‘Tony’)	Keeping busy [aging well]	Keeping active
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‘He'll go out, he'll walk around, he'll come home, and he'll watch TV, and get him sorted out with [inaudible]. I seem to be getting nowhere, he's getting more places than I am.’ (‘Ben’)	Keeping active [aging well]	Keeping active
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‘Well, if you’re, if you’re, getting a job you, you like, enjoy doing, you’re happy in it.’ (‘Wilfred’)	Job satisfaction [aging well]	
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Having a valued role and purpose

‘Point was I’ve helped her sort all her life out and all her bereavement stuff and everything with our view.. I had nothing to do meself y’know cos I was lost, so it gave me something to live for, to help others. So that’s one thing.’ (‘Tony’)	Purpose [aging well]	Having a valued role and purpose
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‘You know, and I just hope I’ll be able to carry on for as long as I can.’ (‘William’)	Carrying on/ enduring [aging well]	Having a positive attitude
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‘But I do like all these people who, they just get on with it.’ (‘Ben’)	Carrying on/ enduring [aging well]	Having a positive attitude
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‘I think it’s about a psychological adjustment to life, to all the aches and pains as you get older, that your health isn't as good.’ (‘Yvonne’).	Acceptance of age related changes [aging well]	Accepting change and circumstance
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‘I’m aged the way I’ve aged. I can't think about it, I don't think about it. I just live one more day to the next and I’m not bothered’ (‘Ben’)	Acceptance of aging [aging well]	Accepting change and circumstance
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‘and erm when you age successfully, you, you’ve got a certain amount of everything, you feel, yeah, this is what I get for, erm, not being too crazy, and I’ve built it back up again and I don’t want to lose what I’ve got again, you see, I’ve built it all up and this time’ (‘Beverley’)
Sense of security (fragile security) [aging well] Mastering Mental Health

Well, aging well, could maybe, having my memory and be able to be .. behaving in a certain way that accepted in society (‘Paul’)
Maintaining cognitive abilities [aging well] Mastering Mental Health

‘Yeh when you asking me questions, that’s all I’m really think about: physical health. I could tell living life well, having lots of money, having a nice house [inaudible]: but I’m more thinking about it y’know personally’ (‘Patrick’)

Physical health is main factor to aging well [aging well] Maintaining physical health

‘Er, you wouldn’t think so, the last six months ,cos obviously I’ve had a bleed in me stomach and it left me very weak’. (‘Tony’)
Physical health problems [aging unsuccessfully] Maintaining physical health

‘Another things is, always locate where your family are and found out what your status is with them.’ (‘Beverley’) Keeping in contact with family [aging well] Connecting with others

‘I’ve been to no groups in the community because I don’t mix with the community.’ (‘Ben’) Social exclusion [unsuccessful aging]
Connecting with others

‘And understanding people better. I do think it needs to start in schools though doesn’t [it]. Teaching people to nurture and care for everything and everybody really.’ (‘Yvonne’) Public education about mental health [aging well] Being Heard and Understood

‘To understand them .. to understand ‘em, erm, erm, just not fob it off, just understand, because .. er, people who have got a mental illness or people who are not very well, erm, they need people to understand.’ (‘David’) Understanding mental health difficulties [aging well]
Being Heard and Understood

Appendix 2: Table of additional quotes *for main themes and subthemes*

Table of quotes

Theme 1: Engagement with life

Keeping Active

'... Just maintaining a good quality of life... Pushing myself to do the things...I suppose everyday things like um ironing washing cleaning making dinner looking after personal needs and what not.' ('Ruth', age 50-55)

'...just being able to cope with things normally, you know .. and .. I get out most days, see friends and .. erm .. I'm a catholic and there's a Mass at 12:15 at the church in town which I go to, and usually do some shopping first, maybe go to the library for a bit ...' ('William' age 70-75)

'... I relate it to myself, like not doing the things you used to do. Yes it can become quite isolating really...Erm It's this age group in your seventies it's harder. Really, cos you haven't got the energy or the willpower to do things like I did. Like I drive but I don't drive far...and yeh I don't go out like I used to do, so that really gets me down in a way.' ('Cathy', age 70-75)

Having a Valued Role and Purpose

'[How can staff support aging well?]'Help them help those who want to go to work and that remember what it is what they want to do.' ('Patrick', age 60-65)

'I think it's, people who have been in a hospital, erm they'd quite like to go back there and be a carer, they always want to feed back to the hospital, ...I received the care and I've now got the care for myself and perhaps a little bit for other people, and they'd like to go in there and they just come in with some fruit or something like that and they sit down and anyone want a conversation... that's what would be good in the future.' ('Beverley', age 50-55)

'And I realise, I realise now, if you do voluntary work though ... are you really appreciated because you're indispensable' ('Wilfred', age 70-75)

'... I had nothing to do meself y'know cos I was lost so it [helping neighbour] gave me something to live for, to help others. So that's one thing' ('Tony', age 60-65)

Theme 2: Attitude to Life and Aging

Having a Positive Attitude

People to go not all like me but some sicker or some healthier ...to go through just getting on keeping on the courage to carrying on with it for the best part. ('Ben', age 55-60)

I'm amazed I look back and I think I never thought I could do this and I always try to learn from... I never really... I might lose situations but I never I never really I always learn from what takes place I always try to find a reason or a meaning or a purpose for things ('Yvonne', age 50-55)

I think just force myself to not give in to the problems and keep doing the things that I'm struggling to do to keep them in a stable place. ('Ruth', age 50-55)

Accepting Change and Circumstance

They're just looking their age. You know in their face. Like I said about all that business. ('Patrick', age 60-65)

[What does not aging well mean?] *'er, I think you panic about how you look you panic how you look, and you try all sorts of things to make yourself younger...*' ('Beverley' age 50-55)

No not in mine there has been no. I'm like anybody just going through life from the life that I was given. No one knows how it's going to change could be better or worse or mortifying or great or rich no one knows. That's the best part about not [caring about] aging, gotta keep in your heart that you're not ...but it's just a bitter thing that you've got to cope with. ('Ben', male age 55-60)

Theme 3: Health and Wellbeing

Maintaining Physical Health

I don't know I think that I'm going downhill. I've just got a lot of problems. I've got physical problems like in my neck and my ankles ('Ruth', age 50-55)

Well I got a relation called [X] and she's 97...And she's aging well and she's still alive. And she's still in good condition. Yeh...in good condition how do you mean? She's pretty fit for her age ('Stewart', age 55-60)

[aging well] what does it involve, it's just that you don't care about yourself ('Wilfred', male age 70-55)

[describing husband who is aging well] Erm well he's keeping fit he's going on his bike all the time and doing a lot of exercises and goes to work on his bike. He keeps fit yeh...Physically ('Moira', age 60-65)

Mastering Mental Health

'... well the illness has got such a grip on so many people, that they can't manage on their own, they've got to, they need the help, you know'
(*'William'*, , age 71)

'But now I'm actually here on this plateau where I can go right you know it's not so bad. And I've worked very hard my whole life for it and to earn it and I think I deserve it really! ... It's been blumming hard work but I've got here so!' (*'Yvonne'*, age 50-55)

'My schizophrenia has been very good. Over the last few years. I've been doing well... Seems to be since I've got older... I'm just not hearing any voices' (*'Moirra'*, age 60-65)

'Well if you say about mentally, er, mental health, I suffer from depression as well as anxiety mainly. I could be happier... if things would have been different in the past, but... But I do try that's why I went to mindfulness, so hopefully I could learn some ways of dealing more with my problems.' (*'Wilfred'*, age 70-75)

'[What would you change to be aging better?]No I mean if I could I'd change the way my mental state can be bad but in a way not really no....Yeh could I would like to but I know it will never be it's not Gods work and it's God's work within God's work and my own problem and me families problem which I don't blame cos [there's] no fault... It's the way it is the way life has got to be no matter how hard it may be. But sometimes you've got to continue through that that foggy bloody mess. And that's the best part of it.[growing older]' (*'Ben'*, age 65-70)

I like my tablets now, I like to feel good, like to take them then I feel successful[in my aging] I'm taking them this time' (*'Beverley'*, age 50-55)

'erm .. erm, erm, their illnesses, and that, the mental illnesses that you know, I think when you take, take a lot of tablets, you basically deteriorate in age' (*'David'*, age 65-70)

Theme 4: Social Connections

Connecting with others

'If I didn't have a partner I'd be so I'd be much poorer if you like emotionally in every sense of the word.' ('Yvonne', age 50-55)

'[Family help to age well]...because they are there for me if I'm unwell and if things are getting me down and things like that.' ('Cathy', age 70-74)

'[describing a friend who is not aging well] And erm got nobody to fight his corner at all and if he's not careful he'll be put back into hospital so he has to do what he, he has to go along with the treatment which is absolutely barbaric and there's nothing anybody will do for him at all and he has to he's brave he has to put on a face and fight the world and erm nobody takes his corner at all.' ('Mary', age 70-75)

'I walk to my sons um two or three times a week and see grandkids and what have you any other time I've had my daughters, so I'm always getting to see them. Otherwise I wouldn't see anybody I wouldn't think' ('Patrick', age 60-65)

'So I mean whereas before for forty or fifty years I have I've been on my own erm isolated, [now] I'm in a family in families that erm say 'oh can you just babysit today?' and you know I would go there for a week and babysit y'know what I mean?' ('Tony', age 60-65)

'...and it's not easy living on your own ... I don't find it easy, you know...and a lot of me friends are married anyway, so, erm, they're not on their own, you know ...' ('William', age 70-75)

'But he's [Psychiatrist] just genuinely kinda alright. You get scared don't you? You know you're going seeing somebody you get on your guard. And before you know it with him I'm telling him things I weren't very sure I was going to tell him. You walk out of there thinking how the heck did he get that out of you then...' ('Patrick', age 60-65)

'I don't know if you know [X]? She's a nurse. We used to have a great friendship together it helped me a lot... you know.' ('Colin', age 65-70)

'They aren't I don't feel I have that problem really because I have support workers you know. I'd be lost if I didn't have them.' ('Cathy', age 70-75)

Being Heard and Understood

'...because you know people, erm who've got a mental illness ... didn't ask for it, you know, and that's where it, you know, families don't, erm, understand, they don't understand, they just think, well, you know, he's off his head him, and it's not that at all, so you, you've got, you know, there's, when you actually, there is a stigma within the family, you know' ('David', age 60-65)

'[Best support for aging well]Erm I suppose again it's about getting people involved that's part of your life that have an understanding about what schizophrenia's about' ('Cathy', age 70-75)

'Just by talking to me and listening, and just see how I'm doing...Just by being there someone to listen to[you]' ('Carol', age 50-55)

I suppose if you had a lifetime of being judged and if you tell people I've told friends I've been mentally ill and it's kinda 'oh right, don't want the kiddies, can't bring the kiddies round' and it's been that kind of experience.' ('Yvonne', age 50-55)

'[discussing people not aging well] Well not doing alright some have more problems some are very poor some are really downtrodden. Because I think they're saying ' oh well you're useless you're no good you're just a senile old man. ' ('Ben', age 55-60)

'[stigma of diagnosis] it's been like four life sentences, because if you commit a murder it's 15 year sentence but I have four life sentences because of my age.' ('Tony', age 65-70)
