

# **Generations** Review



Age Friendly Railways

Ethnicity and Ageing

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# **EDITORIAL**

June 2016

For this edition I have been trawling through old issues of *Generations Review*. It is almost 25 years ago, December 1991, that the first edition was published and Leonie Kellaher and Christina Victor were co-editors of the

inaugural journal. As the Society itself ages, so do the people in it, how do our views on ageing change as a collective and individually. I'll try and pick up some of the key stories from the early issues of the journal over the next few issues and revisit them in light of what we know today. I start by looking at what has changed and what hasn't in relation to the very first article appearing in Generations Review, *Coming of Age* by Malcolm Johnson. What hasn't changed much is the aims of the journal, a vehicle for the transmission and exchange of news, views and debates around the issue of human ageing, a space for expression of ideas which can challenge traditional thinking. To challenge our thinking in this issue I am delighted that we have three articles that typify what gerontology does best, examine issues from the perspectives of older people themselves, examine marginalised or often forgotten about groups of older people and examine the ordinary and everyday experiences of older people. First Dr Iliatha Papachristou and Dr Matthew Roberts examine stroke survivors experiences of care from the perspectives of the patients themselves. Nilufar Ahmed examines the lives of older women living in the London Borough of Tower Hamlets through the use of an intersectional lens to study belonging, citizenship, the family, and religion and how these intersect with place and ageing. I look at older people's use of the

railways, here something that is everyday and ordinary often neglects older people's needs on something that is largely built for commuting, work and the occasional long distance family holiday! Finally, last but not least, we wish to introduce to you Professor Deborah Price, who will be the BSG president from July this year. Some of you will already know her but do you know her that well—read all about her in our pen picture

section.

Enjoy the read and please do send in your articles, stories and comments. Let's upkeep the original aim of Generations Review to challenge traditional thinking and keep it a place for expression of ideas and debates.

**Happy reading** 

**Charles Musselwhite** 

Newton, Swansea, June 2016



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#### A Literature Review on Acute Stroke Care Services from Patients' Perspectives



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occur up to 152,000 times every year and are a main rea-

son for adult disability (Adamson et al., 2004; Towsend, 2012). Over half of stroke patients survive, yet are unable to maintain activities of daily living and therefore need caring from others, such as from family and friends (RCP, 2010). Despite the high rate of survival, previous literature has shown that initially health professionals in acute stroke care settings believed 'nothing could be done' to help patients (Hoffman, 1974). However, studies that later explored health professional experience, found positive perceptions of caring for stroke patients (Pound, 1997). Health professionals perceived their job role as important and satisfying, particularly when the patient went through the process of recovery, e.g. ability to communicate, move independently or ready to go home. This highlighted that 'something could be done' (Pound, 1997). Evaluations of stroke care in the hospital, as well as in the community indicated that services suffered from being fragmented and poorly tailored to patients' needs (King's Fund, 1988). Therefore, a key aspect of evaluating the quality of services is taking patients and carers' views and experiences into account (Pound, Gompertz & Ebrahim, 1994). Understanding how stroke patients and their carers experience admission and recovery is essential if the development of stroke care services is to be effective and functional (Cobley, Fisher, Chouliara, Kerr & Walker, 2013). Therefore, both emotional and instrumental aspects of care need to be assessed when evaluating the health care system (Pound et al., 1995). As little research has focused on stroke patients and carers' experiences, this article aims to provide a review summary on patients

In the UK, strokes and carers' experiences within an acute stroke care setting.

#### **Methods of Search** Strategy

All papers were UK based, focusing on local and national acute stroke care, rehabilitation services and community support. The findings from the literature are organised into the following four sections: Patient satisfaction within hospital and rehabilitation services; hospital admission and duration of hospital stay; meeting psychosocial needs; raising public awareness through information and advice.

#### Patient satisfaction within hospital and rehabilitation services

Patient satisfaction can be broadly defined as 'a health care recipient's personal assessment of health care services and providers' (Rubin et al., 1993). Pound et al., (1994), developed a satisfaction questionnaire based on interviewing stroke patients. Two main themes emerged that otherwise would have not been noted if exploratory interviews had not been conducted. These were recovery and treatment in terms of the amount and at what speed therapy (physio, speech and occupational) could be provided both in the hospital and after discharge. Other areas of dissatisfaction were community support needs to be organised before leaving the hospital and outpatient services. The results from the patient satisfaction study were similar to the health practitioners' views and hence supported the need for improvements in acute stroke care. In the health care sector, patients' satisfaction is vital to establish patient retention, loyalty and increase the likelihood of attending follow-up treat-



ments (Keith, 1998; Reker et al., 2002). Other studies that have addressed patient satisfaction have also emphasised rehabilitation services in terms of availability and the format in which these services are administered (Reker et al., 2002). For example, Bisset et al., 1997 who obtained 125 stroke care patients' satisfaction scores, found that the most dissatisfied areas were in therapy, recovery and community support. In addition, a study by tients and carers' experiences when admitted to hospi-Pound et al., (1999) found 274 stroke care patients scored therapy and recovery lowest on satisfaction. The results were the same at four months and at a 12 month follow up. A study that collected satisfaction data from both patients and their carers found that the carers were dissatisfied with the amount of information provided in hospital regarding the illness and treatment, as well as with social work intervention (Cobley et al., 2013). Given the findings from these studies, it seems that emphasising better communication, discharge planning, and support after discharge for both patient and carer would improve satisfaction with stroke services.

Patients' feedback has been noted to influence clinicians

and managers to aid patient-clinician communication, in turn, improving adherence to medical advice and health-related outcomes (Rubin et al., 1993; Reker et al., 2002). The patient satisfaction survey has been as effective as clinical audits in assessing stroke care, although there has been debate regarding different interpretations of what is meant by satisfaction (Howell, 2007). This has led to a more in-depth approach, which has been to ask the patient to give an account of their own experience. This is considered to provide a broader and more factual account and is an important way to assess quality improvement (Cleary et al., 1997; Jenkinson C, Coulter A, & Bruster, 2002).

#### Hospital admission and duration of hospital stay

The first UK study to report acute stroke patients' perspectives about the use of hospital beds was by Wade and Hewer (1985). A survey of 976 patients identified factors associated with admission to hospital, the dura-

tion of hospital stay and the facilitators to hospital admission. The results indicated that admission and the length of hospital stay are influenced by the severity of stroke and the level of support the patient receives at home. They concluded that the rate of admission would be difficult to reduce as additional home support was not deemed effective. Pound et al. (1995) assessed patal. It was found that patients and carers were relieved to be in a hospital as it was an environment where they would receive care and assistance with daily activities. Patients' also reported being pleased that their carer was unburdened by their admission to hospital. Overall, patient and carer satisfaction with care in an acute setting was high and these experiences were considered important when developing new services such as acute stroke units (Pound et al., 1995).

#### Meeting psycho-social needs

In an early study examining patients and carers' perspectives of health care professionals following stroke,



participants complained of poor communication and a lack of empathy (Christie & Lawrence, 1978). Later studies indicated that communication, respect and the feeling of being valued were major factors in enhancing patient experience in an acute stroke care setting (Pound, Bury, Gompertz & Ebrahim, 1995). It was suggested that the level of individual/person centred care given was equally as important as the clinical care for the recovery process. While most studies have focused on the clinical benefits of hospital admission for stroke patients, assessing outcomes such as mortality and level of disability (Pound 1995), quality of life, including psychosocial needs outcomes during stroke patients hospital admission, has also developed as an area of interest (Isasc, 1978; Young 1994).

#### Raising public awareness through information and advice

Administering relevant information and advice was shown to be important for patients and carers in acute care (Kelson et al., 1999; Rodgers, 2010). Most stroke patients want to be involved with the decision making process during all aspects of their care, but health care services fail to provide sufficient information and advice, which can leave patients and their carer's uninformed and vulnerable. In 2010 a campaign named F.A.S.T. (Face. Arm. Shoulder. Telephone.) was developed which aided patient and carer awareness, informing people to recognise when a stroke may occur and the procedures to follow regarding contacting an ambulance and the timeframe within which admission is crucial. Following that, various medical procedures became known



to the public such as thrombolysis, which increased patient and carer awareness (Harrison, Ryan, Gardiner & Jones, 2013).

In summary, the majority of studies have examined clinical outcomes in post stroke care, while less attention has been paid to the perspectives of patients and carers. However, this review has highlighted the body of literature which has focused upon the experiences of this group. Studies have been classified as those which examine patient satisfaction within hospital and rehabilitation services, hospital admission and duration of hospital stay, the meeting of psycho-social needs of patients and carers, the raising of public awareness through information and advice, and the functional and psycho-social implications of this service-user perspective oriented research. The inclusion of patients and their carers as stakeholders in research gives a better understanding of the perceived limitations and problems of health care for this group, which may otherwise have been overlooked in traditional research. For example, the finding that carers were dissatisfied with the levels of information provided in hospital

Is it a stroke? **Check these signs** 



uneven?

**Hrm** 

OR Does one arm drift down?

Speech Bof fri

OR Does their speech sound

strange?

lime

It's time to call 9-1-1!

(Pound et al, 1999) is important because without service-user feedback, this deficit in information would not be as easily identified by health care providers.

In conclusion, by looking not only at the patients' perspectives but from the family and friends perspectives, areas of health care and services that are perceived as lacking can be addressed and areas that are positive can be maintained. This type of research supplements studies which focus on more clinical factors in stroke treatment and rehabilitation. It provides a more holistic view of the experience of stroke patients and those that care for them.

#### References:

Adamson, J., Beswick, A., & Ebrahim, S. (2004). Is stroke the most common cause of disability? Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association, 13(4), 171–7. doi:10.1016/j.jstrokecerebrovasdis.2004.06.003

Bisset, A.F., MacDuff, C., Chesson, R., & Maitland, J. (1997). Stroke services in general practice—are they satisfactory? Br J Med Pract 1997, 47(425), 787-93.

Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The experience of partners of youngstroke survivors. Disabil Rehabil 2009, 31(20), 1643–51. doi: 10.1080/09638280902736338.

Cleary, P.D., Edgman-Levitan, S., McMullen, W., & Delbanco T,L. (1992).. The relationship between reported problems and summary evaluations of hospital care. Qual Rev Bull; 8(2), 53–9.

Cobley, C. S., Fisher, R. J., Chouliara, N., Kerr, M., & Walker, M. F. (2013). A qualitative study exploring patients' and carers' experiences of Early Supported Discharge services after stroke. Clinical Rehabilitation, 27(8), 750–7. doi:10.1177/0269215512474030

Department of Health. (2007). National StrokeStrategy. Also available at: http://www.dh.gov.

Fitzpatrick, R., & Hopkins, A. (1983). Problems in the conceptual framework of patient satisfaction research: an empirical exploration. Sociol Health Illness, 5(3), 297–311.

Greenwood, N., Mackenzie, A., Cloud, G., & Wilson, N. (2009). Informal carers of strokesurvivors—challenges, satisfactions and coping: a review of qualitative studies. Disabil Rehabil 2009, 31(5), 337–51. doi: 10.1080/09638280802051721

Howell, E., Graham, C., Hoffman, a, Lowe, D., McKevitt, C., Reeves, R., & Rudd, a G. (2007). Comparison of patients' assessments of the quality of stroke care with audit findings. Quality & Safety in Health Care, 16(6), 450–5. doi:10.1136/qshc.2006.022079

Isaacs, B. (1978). Treating stroke: home or hospital? BMJ 1978; ii: 1640.

Jenkinson, C., Coulter, A., & Bruster, S. (2002). The Picker Patient Experience Questionnaire:development and validation using data from in-patient surveys in five countries. Int J Qual Health Care, 14(5), 353–8. DOI: http://dx.doi.org/10.1093/intqhc/14.5.353

Kelson, M., Ford, C., & Rigge, M. (1999). Stroke rehabilitation: patient and carer views. London: Royal College of Physicians, 1999.

Kersten, P., Low, J.T., Ashburn, A., George, S.L., & McLellan, D.L. (2002). The unmetneeds of young people who have had a stroke: results of a national UK survey. Disabil Rehabil, 24(16), 860–866.

Low, J.T., Kersten, P., Ashburn, A., George, S., & McLellan, D.L. (2003). A study to evaluate the met and unmet needs of members belonging to young stroke groups affiliated with the Stroke Association. Disabil Rehabil, 25(18),



Mold, F., Mckevitt, C., & Ffphm, C. W. (2003). A review and commentary of the social factors which influence stroke care. Health Soc Care Community, 11(5),405-14.

Mold, F., Wolfe, C., & McKevitt, C. (2006). Falling through the net of stroke care. Health & Social Care in the Community, 14(4), 349–56.

Moynihan, B., Paul, S., & Markus, H. S. (2013). User experience of a centralized hyperacute stroke service: a prospective evaluation. Stroke; a Journal of Cerebral Circulation, 44(10), 2743–7. doi: 10.1161/STROKEAHA.113.001675.

Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a primary care-based stroke service: a review of the qualitative literature. Br J Gen Pract 2003;53(487):137–142.

Murray, J., Young, J., Forster, A., & Ashworth, R. (2003). Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carer. Br J Gen Pract 2003; 53(495), 803–807.

Pound, P., Bury, M., Gompertz, P., & Ebrahim, S. (1995). Stroke patients' views on their admission to hospital. BMJ. 1995 Jul 1; 311(6996): 18–22.

Pound, P., Ebrahim, S., & Free, R. (1997). Redefining "doing something": Health professionals' views on their role in the care of stroke patients. Physiother Res International, 2(2),12-28.

Pound, P., Gompertz, P., & Ebrahim, S. (1994). Patients' satisfaction with stroke services. Clinical Rehabilitation, 8 (1), 7–17.

Pound, P., Tilling, K., Rudd, a. G., & Wolfe, C. D. A. (1999). Does Patient Satisfaction Reflect Differences in Care Received After Stroke? Stroke, 30(1), 49–55.

Rodger, H., Bond, S., and Curless, R. (2001). Inadequacies in the provision of information to stroke patients and their families. Age and Ageing, 30(2), 129–133.

Royal College of Physicians National Sentinel Stroke Clinical Audit 2010 Round 7 Public report for England, Wales and Northern Ireland. Prepared on behalf of the Intercollegiate Stroke Working Party May 2011 P43

Rubin, H.R., Gandek, B., Rogers, W.H., Kosinski, M., McHorney, C.A., & Ware, J.E. Jr. (1993). Patients' ratings of outpatient visits in different practice settings. Results from the Medical Outcomes Study. JAMA, 270(7), 835-40.

Townsend, N., Wickramasinghe, K., Bhatnagar, P., Smolina, K., Nichols, M., Leal, J., Luengo-Fernandez, R., & Rayner, M. (2012). Coronary heart disease statistics 2012 edition. British Heart Foundation: London. P57

Wellwood, I., Dennis, M., & Warlow, C. (1995). Patients' and Carers' Satisfaction with Acute Stroke Management. Age and Ageing, 24(6), 519–524. doi:10.1093/ageing/24.6.519

Wade, D. T., & Langton Hewer, R. (1985). Hospital admission for acute stroke: who, for how long, and to what effect? Journal of Epidemiology & Community Health, 39(4), 347–352. doi:10.1136/jech.39.4.347

Williams, C., Coyle, J., & Healy, D. (1998). The meaning of patient satisfaction: an explanation of high reported levels. Soc Sci Med 1998, 47(9), 1351–9.

Young, J. (1994). Community care allows patients to reach their full potential. BMJ1994, 309, 1356-7. doi: http://dx.doi.org/10.1136/bmj.309.6965.1356



# 45th Annual BSG Conference 2016 University of Stirling Wednesday 6th - Friday 8th July 2016

#### **About the Conference**

Taking an inclusive approach that recognises that ageing is about all of us, the BSG 2016 conference Communities in Later Life: Engaging with Diversity encompasses a variety of topics illuminating creative and innovative ways of thinking about ageing.

Since ageing is not a homogenous experience, we seek to recognise and embrace diversity from a wide range of perspectives. The conference opens up a space for discussions that not only engage with difference, but also endeavour to make a difference to people's lives. Living well in later life depends upon a web of interdependent conditions, such as the physical and social environment, health, well-being, as well as emotional and cultural understandings of old age.

The conference therefore seeks to develop interdisciplinary and collaborative discussions that advance our understanding of the complexity and multiplicity of ageing experiences. In pursuing this goal, we encourage contributions exploring ways of engaging with diversity to enrich communities and to herald new approaches to ageing policy, research and practice.

#### **Sub-themes**

- Environment and housing
- Health and social care
- Cultural gerontology
- Dementia
- Quality of life
- Innovative methodologies
- Relationships and intergenerational work
- Technology



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#### **Key Dates**

Final registration deadline: 30th June 2016

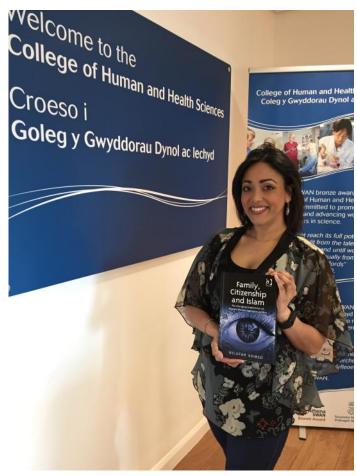


## An intersectional approach to ethnicity and ageing

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It has been belatedly acknowledged that gerontology lags behind other disciplines in understanding the nuances of ethnicity in relation to ageing (Zubair and Norris 2015). Research on minority elders follows familiar tropes of health problems and lack of integration. Static representations of minority groups have led to the enforcement of research agendas onto communities which perpetuate stereotypes. These representations pathologise and 'other' minority communities making no allowances for agency or heterogeneity of experience. Torres (2015) argues that gerontology needs to shift its perspective on ethnicity from typically essentialised ideas about what ethnicity is, to how ethnicity works. She advocates the use of an intersectional framework to examine the multiple meanings associated with ageing. Intersectionality provides a framework to analyse the complexities of individuals' lives; and views categories, such as gender and age, as socially constructed and functioning simultaneously.

In Family, Citizenship and Religion, I apply an intersectional lens to examine the everyday lived experiences of older Bangladeshi women living in the London Borough of Tower Hamlets. It is a qualitative longitudinal research (QLR) study where the same women were interviewed ten years apart. As QLR is a relatively new approach, and research with minority, particularly older migrant women, is rare and often their lack of inclusion in research is justified in terms of them being 'hard to reach', a chapter is dedicated to the methodology of the research. I illustrate how with appropriate and sensitive methodology, people are very willing to engage in research.



book goes beyond familiar constructs of ageing to explore themes of belonging, citizenship, the family, and religion and how these intersect with place and ageing.

Women's use of space remained seemingly constant for decades, but within that time, subtle spatial shifts and changes led to re-evaluations of relationship with place. As women engaged in taking children to school and doing the shopping, they became aware of the growing community, the greater provision of resources, greater accessibility to spaces, and when the time was right for them, they altered their As well as looking at ageing in place, and care and welfare, the relationship with the space in more visible ways. As family



## An intersectional approach to ethnicity and ageing cont...

demands lessened women explored their place in a more active way. In 2001 respondents had been living in Tower Hamlets for an average of almost 20 years (19.7 years) yet

Residential concentration can promote a sense of belonging and positive wellbeing. Women gained confidence outside of the home.

none identified themselves as 'British' in 2010, 50% did so. This sense of belonging arose from a confluence of factors including settled progeny and greater engagement with space. The time taken for a sense of belonging to emerge and for appropriation and ownership of space have implications for discourses and policies on integration and citizenship.

Much of the literature argues residential clustering can have negative consequences on health and access to services. In fact, residential concentration can promote a sense of belonging and positive wellbeing. Women gained confidence outside of the home as many of the second generation became employed in jobs ranging from receptionists and interpreters at health centres, to care workers, pharmacists and doctors across the borough.

The experiences of women show the interactive and mutually constitutive relationship between place and ageing. New services have been established to meet the needs of Bangladeshi elders. After years of sincerely believing they would retire in Bangladesh, many felt it was better to age in Tower Hamlets. Respondents were aware that specialised provisions were not so readily available, not just in Bangladesh but also outside Tower Hamlets, confirming the

attachment to specific place. Importantly narratives demonstrated a willingness to use health and care services for the elderly, challenging notions that Asians prefer to 'look after their own'.

Ageing is socially constructed; as Gullette (2004:101) observes 'we are aged more by culture than by chromosomes'. The book highlights the western inflection of contemporary discourses on ageing. For example, the term 'sandwich generation carer' is generally applied to individuals in their 40s and 50s simultaneously caring for dependent children and aged parents. My interviewees entered in to a position of caring for in-laws and dependent children as early as their teens and often in their 20s. There are different cultural scripts for ageing, Zaima who is 41, says "In Bangladesh people would say I was a very old woman now. I would be different too if I was living there". Significantly, she notes that if she was living in Bangladesh then she 'would be very different too'. In Bangladesh she would adopt the cultural norms of ageing, and perform ageing according to cultural expectations. Thus, it is essential that gerontology is sensitive to cultural contexts.

The literature which explores the gendered aspect of religious identity and practice among Muslims tends to focus on the

Women exercise agency over many aspects of their lives including marriage.

second generation. This book has for the first time explored religious practise among older women. The intersection of religion, time and space alters the religious identification and practises of first generation women. Religiosity and the meaning ascribed to it emerge in multiple ways over the





### An intersectional approach to ethnicity and ageing cont...

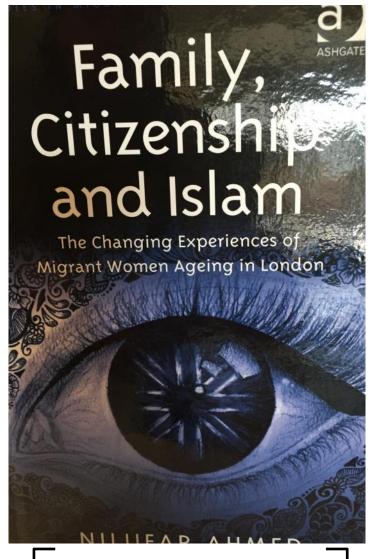
lifecourse and in different social contexts. Muslim women are repeatedly presented as helpless victims of controlling patriarchal regimes; such constructions allow no room for agency and negotiation of patriarchy. Women exercise agency over many aspects of their lives including marriage. Arranged marriages have been commonly criticised in western discourse for the lack of power that women have. However, women's accounts show they exercise choice about and within marriage; and that divorce was neither uncommon nor taboo in Bangladesh for this group of women. This challenges common conceptions about older Muslim women.

Exploring categories such as age, family, religion and care, through an intersectional and longitudinal framework, this book presents an alternative perspective on a community that is so often viewed in terms of disadvantage, showing them to resilient, resourceful as they age.

Gullette M M (2004) *Aged by Culture,* Chicago: University of Chicago Press

Torres, S. (2015). Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives. *Ageing and Society*, *35*(05), 935-960.

Zubair, M., & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts. *Ageing and society*, *35*(05), 897-916.



Nilufar Ahmed (2016) Family,
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#### **Age Friendly Rail travel**

#### **Charles Musselwhite**

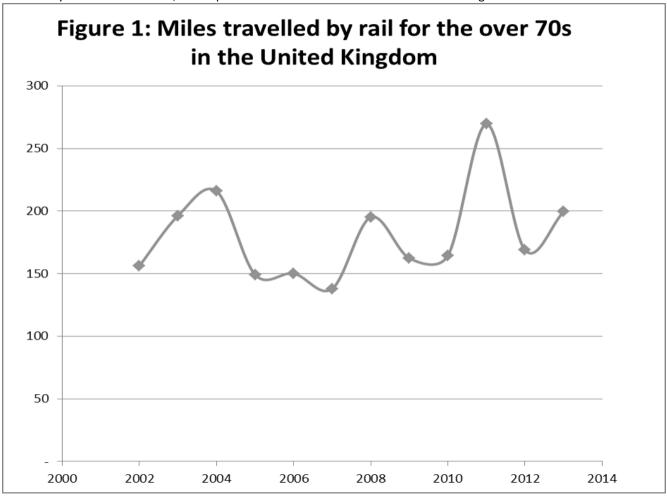
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#### Introduction

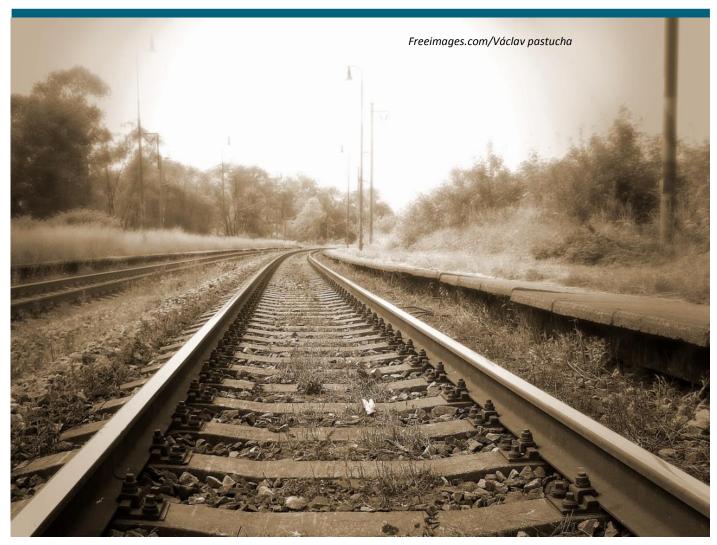
Over the past decade the amount of people using rail has grown significantly in the United Kingdom (UK), both absolutely and in terms of percentage of overall distance travelled. In the United Kingdom, rail travel has increased 67% between 1995/97 and 2013 (DfT, 2014). The increase is especially noticeable in early and middle aged adults and is not anywhere near as pronounced in later life, indeed those aged over 70 years of age have stayed around similar levels, fluctuating between 130 and 200 miles (except a peak of 269 miles in 2010) per person per year, accounting for between 4 and 6% of miles travelled. Figure 1 shows the recent trends in miles travelled by rail for the over 70s, with a peak in 2012 of over

260 miles and a trough of below 150 in 2007. There is little explanation for these peaks and troughs. Across the lifecourse, train usage begins to fall from 60 years onwards (DfT, 2014), some of which is linked to decreasing travel as commuters or for work purposes (DfT 2014). Overall, there is very little research on older people's use of railways but I've tried to highlight below what there is.

Older people have higher satisfaction with their train travel including being positive about price and the overall journey experience. This maybe because of making more recreational journeys than the average train user – leisure users are more satisfied than those using it for work and commuters across



#### Age Friendly Rail Travel cont...



all ages, for example (Ormerod et al., 2015). Searching through passenger data from Passenger Focus (2015) reveals the following:

Getting a seat on a train is a higher priority for older passengers than it is for younger passengers and from 60 years onwards it becomes more important than cost of the ticket.

Older rail passengers are more likely than rail passengers in general to want to be kept informed about the journey and any delays (Passenger Focus, 2015) and

Older rail passengers compared to younger and middle age rail passengers, are less likely to be concerned about free wi-fi being available.

There is more concern with the state and cleanliness of the carriage and of the toilet facilities from 65 years onwards (Passenger Focus, 2015).

Passengers aged over 60 prioritise these over length of journey and frequency of services, possibly showing their more intermittent and leisure use.

Station design is also vital for older people. For those with mobility impairments or want a little help going upstairs with heavy luggage, we have seen lifts being put in now on most principal stations, but little consideration has been made as to the location of the lifts which are often at one end of the platform requiring much walking to and from them to get the train which often stops in the middle! Stations naturally must have indoor waiting areas and toilets wherever possible. Older people can feel more vulnerable on trains and station and visibility is key to this; older people feel more vulnerable and are less likely to use the station where there is a lack of staff, lack of other passengers, lack of lighting and dark enclosed waiting areas (Cozens et al., 2004). This can be placated somewhat through better design. An excellent project was carried out on the valley lines in Wales which resulted in better designed stations. In particular, Dingle Road was re-designed from a station that contained two old enclosed shelters to one that contained a see-through shelter which improved feelings of

#### Age Friendly Rail Travel cont...



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safety for all age groups (Cozens et al., 2004). Consideration of platform barriers in and out of the station must weigh up pros and cons of accessibility, allowing family, friends, carers and helpers to carry luggage and help on and off the train without the need for a ticket and without the need for older people to make mistakes with the barrier system, causing anxiety and stress.

Ticketing is complex in the UK for all everyone, let alone people either (1) not used to using the railway and not using it regularly, as many older people fit this category as they are less likely to be using the rail regularly for work, for example; (2) who suffer some cognitive challenge, which again many begin to acquire as we get older. Making tickets more straightforward and legible is needed, both in terms of who can use the ticket when and where (the validity of the tickets allowed on which services is highly complex) but also on the ticket printout itself. Allowing a single ticket or card to move between different modes of transport, say between bus and train and certainly between buses is needed. The Oyster card in London is a great example of this. Consideration of free or concessionary travel should be investigated. The free bus pass in the UK for older people, for example has been hugely successful in keeping older people mobile and in turn keeping them connected, fit and healthy (see Mackett, 2013 for an overview). A recent report by Greener Travel (2014), in conjunction with KPMG LLP, used DfT guidance on economic appraisal and found for every £1 spent on the 'free' bus pass for older people, £2.87 is returned back into the economy (Ormerod et al., 2015).

Older people more than other groups value the importance of staff to help them at rail stations and on train services. They are more likely to trust information if it is given from authority figures, for example railway staff, and like the staff to be friendly and approachable (Musselwhite, 2011). They use staff for timetable information, especially if trains get delayed or things go wrong, whereas other groups are more likely now to use mobile ICT and apps (Musselwhite, 2011). They use staff for backing up information they see on screens or hear over the announcements which they trust less than younger groups. They also often want staff available should they need help carrying cases.

So, overall an age friendly railway service must have the following:

- (1) Railways must be accessibility. The railways station and train must be accessible, especially help with mobility but also in terms of facilities, and crucially, seating and toilets. If services are likely to be full or a seat cannot be booked in advance or a train does not have toilet facilities, older people need to be made aware of this and be given opportunities to alter or change travel at no additional cost.
- (2) Railways must have integrated and simple ticketing. Clear ticket labelling and pricing and the possibility of integrated Oyster Card style ticketing should be investigated. Concessionary or free fares would really benefit older passengers and should be considered.
- (3) Railways must have available helpful and friendly staff. Having staff that are trained to deal with issues that older peo-



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#### Age Friendly Rail Travel cont...

ple might face, that have the time and patience to deal with enquiries and concerns are crucial. Staff must be on hand to be able to help escort passengers and their luggage to their seats without much hassle and without making older people feel a burden. Staff training should emphasise an age friendly approach, as has been undertaken by many bus companies, for example. If no staff are to be available, again older people need to be alerted and opportunities to make alternative travel, at no extra cost, be offered.

- **(4) Railways must be safe.** The railway station and train itself must feel safe to use. Presence of staff can aid this, but also design is crucial with visibility being the key. Where staff are present they must be visible and approachable for the passengers.
- **(5) Railways must provide an attractive service.** The railway service should be clean and presented in an attractive manner.
- **(6)** Railways must provide an intuitive, information based system. Clearly labelled exits and entrances placed on stations. Clear instructions on services with updated information on delays and changes to the service are needed at all times. Information often needs verifying by staff members and this

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should be done as a matter of course not only when something goes awry.

#### References:

Cozens, P. M., R. Neale, J. Whitaker, and D. Hillier. 2004. "Tackling Crime and Fear of Crime While Waiting at Britain's Railway Stations." *Journal of Public Transportation* 7 (3): 23-41 http://www.nctr.usf.edu/jpt/pdf/JPT%207-3%20Cozens.pdf

Greener Travel (2014) Concessionary travel costs and benefits September 2014. Available at: <a href="www.greenerjourneys.com/bus-pass/research/">www.greenerjourneys.com/bus-pass/research/</a> (accessed 21 March 2016). DfT (2014) *Transport Statistics Great Britain:* 2013. DfT: London.

Mackett, R. (2013) The impact of concessionary bus travel on the wellbeing of older and disabled people. Transportation Research Record 2352, 114–119.

Musselwhite, C. (2011) <u>Successfully giving up driving for older people.</u> Discussion Paper. International Longevity Centre - UK.

Ormerod, M. Newton, R., Philips, J., Musselwhite, C., McGee, S and Russell, R. (2015). How can transport provision and associated built environment infrastructure be enhanced and developed to support the mobility needs of individuals as they age? Future of an ageing population: evidence review Foresight, Government Office for Science, London, UK.

Passenger Focus (2015). National Rail Passenger Survey. Open data accessed via <a href="http://data.transportfocus.org.uk/download\_data/">http://data.transportfocus.org.uk/download\_data/</a> (21st March 2016)(pedometers)



# Coming of Age Again

# Charles Musselwhite reflects on Malcolm Johnson's article Coming of Age published in the inaugural Generations Review, December, 1991

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Generations Review (GR) first appeared almost 25 years ago in December 1991. Edited by Leonie Kellaher and Christina Victor, GR was, it was hoped, to become an important way of carrying the debates and questions about human ageing and later life and as such an exchange of news, views and debates. As GR comes of (an) age I revisit it's first article, Coming of Age by Malcolm Johnson, who was, incidentally, recently awarded lifetime achievement award by the British Gerontology Society in 2014. The article is timely to revisit, it serves both as a benchmark of where we were then as a discipline, and indeed as a society and how we treated or understood older people and also where we were going. The article was a text of a speech given at a launch event of Age Concern's Coming of Age Campaign back in 1990. In his beautifully written speech Malcolm is anxious, if not on occasion angry, at the lack of progress made across society as he reflects on issues researched and covered in his own career. He describes how his research career in the field began as a junior researcher alongside Peter Millar (later Professor of Geriatric Medicine at St George's Hospital) working to Professors Margot Jeffreys at Bedford College and Norman Exton-Smith in 1966 on a project looking at the Unmet Needs of People over the age of 70. The project, he says, was largely unremarkable, they found similar results of previous studies such as Barabra Robb in her book Sans Everything, Perter Townsend's excellent mapping of socio -medical issues in later life and Sheldon, Brockington and Lempert's pathologies, that largely older people's needs went unmet whether at home or in institutions. However, it made Malcolm, and Peter realise that what needed to change, as much or indeed above and beyond, identifying, challenging and trying to resolve unmet need, was a general attitude that older people were largely and erroneously seen as sick, dependent and impoverished; a need therefore to understand the positive side of ageing. Not everyone who ages has such a bad time of it and he especially notes the difference between the wealthy and the poor with this respect. The positive side of ageing is he says not reflected in general society and in his speech draws on poetry, arts and literature to highlight just

how this attitude manifests itself throughout culture: He describes the grotesque mourning of the loss of carefree independence and youthful beauty in Betjeman's Late Flowering Lust, "I cling to you inflamed with fear, as you now cling to me, I feel how frail you are my dear and wonder what will be!" From Victorian times he cites Longfellow, "O give me back the days when loose and free to my blind passion were the curb and rein...In an old man though can'st not wake desire?" More recently he described how Philip Larkin gloomily portrays old age in The Old Fools, "What do you think has happened, the old fools, To make them like this? Do they somehow suppose it's more grown up when your mouth hangs open and drools."

Has our view of this changed? In research terms, I do believe generally that we unpick gerontology better than ever before, we do critically engage with ageing and what it means. Critical gerontology, whether you subscribe to all its' beliefs of not, has been central to offering up a reflective mirror and reflexivity to researching human ageing. It is no longer acceptable to view older people as a homogenous dependent and needy group. We must be cleverer as researchers than this. Does it always happen? In research I would argue there are still examples of people studying ageing from outside of gerontology (and not all) that still fall into this trap. It is our duty as gerontologists to work with such researchers to change these attitudes. In society in general, how has culture changed? Do we still see ageing so negatively as Malcolm Johnson suggested in 1991? A recent article in the Journal of Advanced Nursing (Kelly et al., 2016), suggests perhaps Malcolm should have looked more closely at contemporary rock and pop lyrics, for example Bob Dylan's Forever Young 'May your hands always be busy. May your feet always be swift. May you have a strong foundation, when the winds of changes shift. May your heart always be joyful. And may your song always be sung. May you stay forever young'. Or Sophie Tucker's Life begins at Forty 'You see the sweetest things in life grow sweeter as the years roll on Like the music from a violin that has been well played upon And the sweetest smoke is from a mellow, broken and

#### Coming of Age Again cont....

old pipe And the sweetest tasting peach is one that's mature, round and ripe'. Despite this still around two thirds of the lyrics examined were by Kelly et al. (2016) were negative, for example Green Day's *The Grouch*, 'I was a young boy that had big plans. Now I'm just another shootty old man. I don't have fun and I hate everything. The world owes me, so freak you. Glory days don't mean shoot to me. I drank a six pack of apathy. Life's a bitch and so am I' or Pulp's *Help The Aged* track which asks the listener to give the aged hope and comfort "cos they're running out of time".

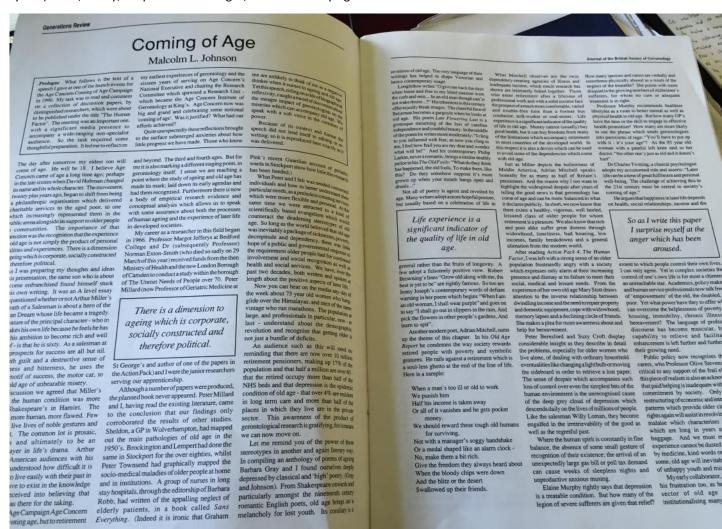
We are still acutely aware of the effect of poverty on an impoverished later life that Malcolm noted in 1991. Have times changed over the past 25 years? I'm not so sure; the divide between those living in the top and bottom quartiles of deprivation in the United Kingdom still differ by 15 years in terms of disability free life expectancy (see AGE UK, 2013, for example, lowest deprivation=70 years, highest deprivation=55 years). And, finally, despite these changes, the most worrying

aspect is how we deal with ageing in society (including our own ageing) is still riddled with problems and issues. Look at the research findings on poor care for older people (e.g. Vizard and Burchardt, 2015) those needs are still going unmet as Malcolm pointed out in 1966 and drawing on research from the 1950s.

Kelly J., Watson R., Pankratova M. & Pedzeni A. - M. (2016) Representation of age and ageing identities in popular music texts. *Journal of Advanced Nursing* 72(6), 1325–1334. doi: 10.1111/jan.12916

Johnson, M.L. (1991). Coming of Age. *Generations review,* 1 (1), 2-4

Vizard, P. and Burchardt, T. (2015). Older people's experiences of dignity and nutrition during hospital stays: Secondary data analysis using the Adult Inpatient Survey Case Report 91. London School of Economics.





#### **Debora Price**

Professor of Social Gerontology at the University of Manchester, where I direct MICRA, the Manchester Institute for Collaborative Research on Ageing.

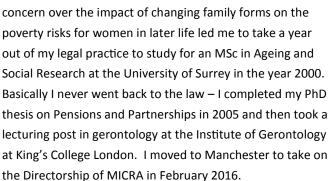
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#### Describe yourself in three words.

Collaborative; Committed; Enthusiastic

# How did you get here today (i.e. career/research)?

I've had a rather unusual path to gerontology — I started my working life as a barrister, having read law at Trinity Hall, Cambridge. I practised law for about 15 years, ultimately becoming a founding member of Coram Chambers, a set of barristers' Chambers specialising in family law. I had particular expertise in pensions and my



#### What's the best piece of advice you've received?

From Jo Moran-Ellis, who is now a Professor of Sociology at the University of Sussex. When I was a PhD student she told me that you can't know everything. It was very helpful in calming me down! I've also received two brilliant pieces of advice from Jill Manthorpe who is a Professor of Social Work at King's – to keep all stakeholders on board with what you are doing at all times; and that you should aim to have outputs proportionate to funding. These have been very good rules of thumb through my career.



# Who is or has been the most influential person in your career?

Again two – Professor Sara Arber, who supervised my MSc thesis and then my PhD. She is a fantastically inspirational person and a brilliant manager, and I really have little doubt that she is the reason I have ended up in academia and in gerontology. And then Professor Karen Glaser who directs the Institute of Gerontology. She was a natural leader and an absolutely fantastic collaborator, colleague and friend for the ten years that we worked together. I have learnt a great deal from both of these inspiring women.

#### What's the best book you've ever read?

Too many 5\* books to name but 2016 favourites have included Stoner by John Willliams, a pretty much flawless novel about the ordinary life of an ordinary man; and Theresa Smith at the Court of Heaven by Polly Walshe – a brilliantly dystopian book about end-of-life choices, pure genius.

#### Who's Who—Debora Price, Professor of Social Gerontology at the University of Manchester

# Best or most influential article you have read, you'd recommend to others to read?

Probably something by Danny Dorling, who I think has a unique take on inequalities and the ability to express complex social ideas in very clear language. I love reading his work.

#### What do you do when you are not working in ageing?

Hike, read, play golf, go to the movies and theatre, and watch some truly dreadful TV. Bad TV is my secret pleasure.

#### Best projects you have been involved with and why?

I've been involved in many but I think 'Behind Closed Doors' is still my favourite, examining money management among older couples behind the closed doors of the household. We are still getting publications out from it six years after it ended. It offered great insight into things that are really kept very private within the home, even taboo.

#### What's the future for ageing research do you think?

Collaborative research I am sure, especially across the life sciences, medicine, humanities and social sciences. Within these collaborations I'd like to think that the social sciences will become more important as we grapple with the various challenges that accompany ageing societies. I think we need to think more about new inequalities and new types of inequality in a rapidly changing world. We also need to think both about how to bring such disease and treatment breakthroughs as there are to all people of the world, but simultaneously how health and well-being can be sustained in later life in the absence of disease and treatment breakthroughs. There will be no shortage of important research questions for those of us in gerontology as societies and individuals age at an unprecedented pace through the coming century.

The British Society of Gerontology's (BSG) Emerging Researchers in Ageing (ERA) provides students, early career academics, researchers, and practitioners with opportunities for learning, networking, and mentor support. We also welcome academics, researchers, and practitioners who are making a mid-career change to ageing studies. ERA co-chairs develop programmes and events informed by the suggestions and stated needs of our members.

For more details visit

http://www.britishgerontology.org/era.html



# JOIN THE BSG TODAY!

Ageing research is increasingly high profile, nationally and internationally.



Consequently, those in universities and in organisations working with older people, will benefit from joining the British Society of Gerontology. The Society gives members access to a multidisciplinary forum and network of like minded people dedicated to applying the knowledge gained through research and practice to improving quality of life in old age.

Membership of the BSG brings you into a community of academics and practitioners interested in a wide range of issues related to ageing. In particular, membership:

- Facilitates access to dynamic and up-to date debates about ageing and ageing studies our members are involved in cutting edge research, policy and practice and are very willing to share their perspectives with you
- Members have access to a number of social media platforms blog Ageing Issues; twitter account; YouTube channel Ageing Bites; LinkedIn Group
- Entitles you to significantly reduced rates at the Annual Conferences of the British Society of Gerontology
- Gives access to our vibrant group of Emerging Researchers in Ageing (ERA), which includes students, postdoctoral researchers and those established in their careers but new to field of ageing, who meet regularly to discuss research, policy and practice and support one another in their careers
- Access to our mailing list (BSGmail) to enable you to keep up-to-date about conferences, seminars, teaching courses, and research about ageing and ageing studies
- If you are a student, postdoctoral or unwaged member, you are entitled to apply for a conference bursary, for example, to cover costs to attend our annual conference
- Entitles you to substantially reduced subscription rates to the following peer reviewed journals: Ageing and Society and Journal of Population Ageing
- Provides you with access to all areas of the BSG website, including the Membership Directory and Members Only pages

#### How can I join?

Visit the website and fill in the registration form online and we will do the rest!

www.britishgerontology.org/join



# **OUR VOICES**

The experiences of people ageing without children

ow will, and should, older adults without children approach their later years? While many issues affecting older people have received attention, two questions that remain under-researched and under-reported are, why more people over 50 are entering later life without children and how this will affect them. One in five people over 50 are not parents, while others enter later life without children because of death, estrangement or distance. By 2030 an estimated 2 million people over the age of 65 will be without adult children. An unspoken assumption underlying policy and planning on ageing is that older people have children and grandchildren who can provide the required help, support and care. Those without children are not considered.

OUR VOICES
The experiences of people ageing without children

Our Voices, a research report, based on focus groups, interviews and case studies, highlights the concerns voiced directly by people ageing

without children. Six main themes emerge from the experiences that participants describe in their own words: feeling invisible; being judged unfavourably for not having

children; having no one 'to tell your story' when you are no longer able to tell it yourself; the 'trigger-point' significance of becoming a carer oneself; the issues of practical support; and losing touch with other generations. The report examines each of these themes and the many factors contributing to them, which include false assumptions, ageism, language, political narratives focused on 'hardworking families', and the

'They won't let me go home from hospital unless there's a named person to pick me up...
I tell them I don't have a name to give and they look surprised as if it never happens. Perhaps it is just me who doesn't have anyone.'

fact that many people ageing without children belong to groups experiencing other forms of discrimination, including racial discrimination, and discrimination against LGBT people. Besides the comments participants voice on particular points, several personal experiences of ageing without children are narrated at greater length in the report.

There are no easy answers to these questions, but the report identifies a number of solutions that people ageing without children propose themselves. These include measures to help central and local government planning take account of present realities and future needs, to ensure that medical and social care services are sufficiently informed and equipped to provide the required support, and that advocacy services are available for people ageing without children. Steps are also recommended to help people to plan adequately for their later life, to broaden public understanding of the issues, and to invest in intergenerational programmes. Finally, the report identifies a number of areas where further research is needed.

Our Voices: The experiences of people ageing without children is published jointly by the Beth Johnson Foundation and Ageing Without Children. Printed copies of the report are available from The Beth Johnson Foundation, Parkfield House, 64 Princes Road, Hartshill, Stoke on Trent, ST4 7JL or by emailing admin@bjf.org.uk

The report can also be downloaded in PDF form from www.bjf.org.uk or www.awoc.org







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