ROUTLEDGE KEY THEMES IN HEALTH AND SOCIETY

Older Citizens and End-of-Life Care

SOCIAL WORK PRACTICE STRATEGIES FOR ADULTS IN LATER LIFE

Malcolm Payne

ROUTLEDGE

'Challenging current practice models in social work and social care, Payne explores the concepts of citizenship, social work and participative interdependence and skilfully demonstrates how these could – and should – be applied to practice with older people at the end of life. This groundbreaking work is essential reading for practitioners and academics alike.'
Sue Taplin, *University of Suffolk, UK*

Older people are, like younger people, citizens in the communities of the nations in which they live. This book sees ageing as a life journey that incorporates a process of citizening, in which people build their identity as part of their family and community. But the social experience of illness, frailty, disability and reaching the end of life may de-citizen older people by devaluing the social identity that comes from continuing social engagement. We de-citizen older people by emphasizing dependence on services and their cost to public expenditure instead of valuing the interdependence of participation and mutual respect. This book argues that older people retain full citizenship for the whole of their lives, up to the moment of death; but what does this mean for health and social care?

In this groundbreaking book, Malcolm Payne argues that social work with older people must build re-citizening practice strategies in order to value both the common and the special aspects of the citizenship of older people. Current models of social care and social work create dependency, rather than relying on values of participative interdependence. The failure to recognize the end of life as a crucial element in all social care and social work for older people means that the lessons learned in providing palliative and end-of-life care in healthcare have not been transferred to social care, and the priorities of end-of-life care have not been adequately encompassed in social work with older people.

Malcolm Payne is Emeritus Professor, Manchester Metropolitan University and Honorary Professor, Kingston University; formerly Director of Psychosocial and Spiritual Care, St Christopher's Hospice, London.

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INTRODUCTION

How long are you going to live? Another way of asking this question is: when are you going to die? None of us can know the answer to these questions, however you ask them; but for many of us statistics suggest that it will be longer than our parents' generation and perhaps longer than we expected when we were children. What are we going to do with that longer life? How are we going to live it? Perhaps we will live longer than we want: in many societies across the world, people are talking more about assisted suicide when they become old and ill. So there are important questions to ask about how we are going to live with ageing and death in societies across the world, and social workers are going to be part of people rethinking social assumptions about ageing and death. We have to equip ourselves and the social care services to be part of this job of rethinking.

The UK Office for National Statistics (2015) summarized the average length of lives in the UK with statistics covering the years 2012–2014 as follows:

- A newborn baby boy could expect to live 79.1 years and a newborn baby girl 82.8 years if mortality rates remain the same as they were in the United Kingdom in 2012–2014 throughout their lives.
- In 2012–2014, a man in the UK aged 65 had an average further 18.4 years of life remaining and a woman had an average further 20.9 years of life remaining.
- The most common age at death for men was 86 and for women was 89.
- Life expectancy at birth in the UK has increased since 1980–1982 by 13.5 weeks per year on average for men and 9.8 weeks per year on average for women (Office for National Statistics, 2015).

Factual statements like this do not tell us anything about how people live these lives at any stage of the ageing process. These particular statistics tell us nothing about the changes that have taken place in ageing over the lives of people who are currently reaching later life or the changes that they will see in the future. People's perceptions of ageing, either in society in general or among people in later life, are relevant to how older people see themselves and how they live in society. Such generalized information also tells us nothing about inequalities

between different groups of older people. Inequalities among people in later life are particularly important to health and social care services. This is because preventive services may need to do more to improve the factors that contribute to ill-health and social difficulties in later life. Also, services for older people adversely affected by unequal life outcomes may need to do more, although work to improve everyone's health and social care is important too.

What these simple statistics do tell us, however, is something about the extent of the task, and alongside that the importance of consistency of our concern and our provision over quite a long slice of people's lives. If you take 65 years of age as a marker of the starting point of older age groups, as pension policies and public services in many countries do, social workers with older people can expect to be working with people over about 20 years or more of their lives, and that period is likely to rise over the next years and decades. Looking at these figures the other way, social workers with older people can expect to be helping people at the end of their lives from around their mid-80s onwards. This book asks: what is the implication for the way in which they organize their practice of these realities about dying in old age?

This book aims to help social work practitioners and students who work with older people take responsibility for and work with the personal and social significance of the end of life in later life. It also presents an approach to social work with older people that integrates end-of-life care throughout their care career; this is not yet commonplace in social care services. Instead, we are still concentrating on operating person-centred care planning systems, when it is also important to help with the human and family consequences of ageing and the end of life.

Integrating social care with healthcare is an important policy objective in the UK and relevant to practice anywhere. Part of this is an aim to develop social care involvement in end-of-life care (National End of Life Care Programme, 2010). Again, this is relevant to social work and healthcare practice everywhere, since end-of-life care is important for many healthcare systems across the world; it is also a firm objective of the World Health Organization (World Health Organization, 1998). So a book about social work practice with older people that incorporates end-of-life care connects with and emphasizes current trends.

I also advocate a citizenship social work with older people. Marshall and Tibbs's (2006) analysis of citizenship social work with older people is well established in social work. It emphasizes the importance of their participation in every aspect of human living in their society including, but not limited to, decision-making about their care. But we need to go further than that, recognizing the complex ways in which citizenship is both lost and also built up in social processes. Our practice is part of the process that can help to develop rights towards fuller citizenship for older people. In Chapter 2, I argue for a practice to:

- oppose de-citizening older people by taking away their human rights;
- re-citizen their lives by building on their human rights to a successful later life leading to their dying well.

My account of social work with older people (Payne, 2012) took up citizenship ideas because they implement my analysis of social work as a humanistic enterprise (Payne, 2011). This puts our recognition of the humanity and human rights of all the people that social work serves at the centre of our practice.

It is no longer possible to practise social work with older people adequately within the professional roles allocated to social workers by community social care services, hospitals and

hospices. Instead, social workers must return to their profession's historic aims to be a part of a community that responds to and cares for older fellow citizens. To do the best job for people as they age, we have to help everyone, no matter how young, grapple with thinking about and planning for ageing and the end of life. We certainly have to help older citizens move with grace and forethought towards their death. You lose rights if you do not plan to retain and build them. Social workers must also act as citizens to be part of the citizenry. It is not enough to do the jobs of assessing older people and their carers to decide what public services are to be allotted them. It is not enough just to pick up social needs generated by ill-health or by the need for safeguarding older people against abuse and neglect. These established professional service roles are valuable, but social workers also need to bring their understanding of people's experiences in later life into the community. We all make our own journey through ageing, and social workers can help everyone plan to age well as they travel their path through life. And ageing well also means dying well, because dying is an important part of the journey in old age, and therefore an important part of the journey of the family and community around the person who dies.

We need major change to provide a good quality of life for all older people that enables them to die well. People sometimes talk about 'a good death' but dying is a process that goes on for some time, not an event that takes a few hours, so I prefer to talk about 'dying well'. Such changes in services are needed across the world, because most societies are experiencing an increase in the proportion of older people in their populations. It is welcome that many people live a longer and more valuable life; part of that life is dying well. Dying well means having lived your life well.

On the other side of the equation, people worry about current assumptions about care for older people. Can we live a working life, finance our later life and make a place in our lives to care for older people in our family and community? Is it impossible to age and die well and to find the care that we might need to do so? Pickard (2015) estimates that the demand in the UK for help by unpaid carers who are adult children of older people with disabilities will exceed supply in 2017, and by 2032 that there will be a shortfall of 160,000 carers. New technology that enables surveillance for older people's security and provides support for their needs in their own homes will bridge some of that gap. But responding to care needs disclosed by new technology will still rest on families and communities. It is not clear that improvements in technology are the full answer the older people's care needs, and it is clear that human caring is still going to be in the front line.

Governments are concerned about how the state should respond to the social pressures that the demographic turn to longer life will create. It may render traditional patterns of the life course and care within it inadequate, because a 'care deficit' (Hochschild, 1995) means that we can never provide enough care. One reason is that care for older people requires significant state provision. Paying for care in the market is impossible for people who are unfortunate enough to be among the minority who need the most extensive services. Current social policy relying on neo-liberal economic thinking denies this reality, and consequently accepts inadequate policy and services which, in turn, makes relying on present care practices insecure.

But that is not the most important reason why there will always be a deficit in the provision of care. To understand this, we must think about how most people would like to live in their old age, and how they would like to die. A UK study of older people's views about the services they receive when they have 'high support needs' (Katz *et al.*, 2011) makes it

clear that we can do more to maintain people's citizenship by promoting good relationships in their families and communities and helping them remain in control of as much as possible of their life experience. Most people would prefer to live a generous period of healthy old age in a familiar home in the community where they have emotional ties in longstanding relationships, and they hope to die fairly quickly in reasonable comfort, preferably in the security of their own home, surrounded and cared for by people whom they love and who value and respect them. The reality is that many people experience a long period of declining health and fitness, cared for 24/7 by a spouse or partner. Other family members may be unable to provide much care either because they are themselves ageing or because of family and work commitments, which may also mean they live at a distance. Many people die after a health problem during which they are admitted to hospital in an emergency and they die in a busy ward without the serenity that we might wish to have in our last hours. Alternatively, they are discharged without much planning to a care or nursing home that they would not have chosen and where they die shortly afterwards.

Building end-of-life care into social work with older people: Practice strategies

Part I of this book shows how social workers have important social roles and valuable practice skills to offer older people who are approaching the end of life. Social work has made a big contribution to the specialist areas of end-of-life and palliative care, which have several decades of experience in working with dying and bereaved people, their families and carers. Social workers working with older people can learn from that specialist experience.

You may feel inhibited in building up end-of-life care by the workload of the main social work role in services for older people. Good assessment for person-centred care planning is important for the justice and quality of social care for older people. But practitioners feel the constant slog of targets for completing the bureaucratic requirements for providing and organizing services within the seriously underfunded social care systems. It seems like a constant struggle to do something meaningful to help carers where older people are struggling themselves with physical frailty and encroaching psychological, social and spiritual problems. A few years ago I was involved in a number of projects where teams of social workers in UK social care services for older people were encouraged to work on end-of-life care issues with their existing caseloads. Many practitioners were extremely cautious: how could they possibly take on these difficult issues as well as meet their targets for completing assessments, and difficult safeguarding issues? Some were fearful of being unable to deal with powerful emotions of grief and anxiety that might go with working with people who are dying. Some were also ambitious. This was what they had come into social work to do: not just care planning and service delivery, important though it is to do these tasks well, but helping people make the best of living well, even in poverty and struggle. And making the best of dying well, in spite of the hindrances to it.

Three important aspects of making those projects work were, first, a commitment from senior management downwards to supporting their staff in taking on that additional burden; second, additional training from experienced practitioners in end-of-life care to help them feel confident in doing this work; and, third, the end-of-life pathway introduced by the National End of Life Care programme, which helped them conceptualize their role in the range of services available for people as they approach the end of life. Many of these points

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