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The Changing Face of Volunteering in Hospice and Palliative Care

AN INTERNATIONAL PERSPECTIVE

EDITED BY ROS SCOTT | STEVEN HOWLETT

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Foreword

The discipline of palliative care is primarily focusing on the patient who has the disease—whether it be cancer or other chronic diseases. It is crucial to take psychosocial issues into consideration in order to deliver optimal palliative care. The patient-centered approach ought to be combined with a disease-centered approach in order to deliver optimal care. This combined approach is expected from the patients, the family and from society.

Most textbooks in medicine focus mainly on the disease approach. This approach is well covered, including new knowledge about the pathology, the epidemiology, the diagnosis and the treatments of the disease. However, knowledge and competence in psychosocial issues are needed in order to combine the disease and patient centered approach; this combination is seen in “early integration of palliative care.”

Already, in 2002, the World Health Organization (WHO) changed some of the content of their definition of palliative care. It clearly states some fundamental issues related to organization, content and competence in palliative care:

- ◆ For patients and families “facing the problems associated with life threatening illness”
- ◆ From an organizational perspective: “palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life”
- ◆ It should be performed “through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment”
- ◆ It constitutes a broad approach to the patients’ assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

Four main issues are debated today with background in the content of the WHO definition. These issues are also relevant for the need of psychosocial care:

Integration of palliative care early in the disease trajectory

- ◆ A correct use of diagnostic tools , and methods to identify patients in need of treatment
- ◆ Family involvement – a life threatening disease will also have impact on the family
- ◆ Patients with life threatening diseases are often suffering from several symptoms and signs in parallel of physical, psychosocial and spiritual nature

Psychosocial issues in palliative care is content wise one of the main pillars of modern palliative care.

This book covers main areas of psychological and social care and the important role of volunteers. Many of the chapters give excellent updates, and more than that; the book is discussing fundamental approaches to patient care and health care. The need for a community-based approach involving volunteers is necessary in order to reach a basic goal in palliative care to give the patients the possibility to stay at home as much and for as long as possible, and to die at home if desired. The latter goals will probably need to be facilitated by involving end of life care in community care as well as a part of the national public health policies. This book is therefore highly relevant for clinicians in general and even more for palliative care specialists and all those who work in palliative care.

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List of Abbreviations

AHD	Ambulante Hospizdienste	Bundesinstitut für Gesundheitswesen	
AIDS	acquired immunodeficiency syndrome	GP	general practitioner
ART	antiretroviral therapy	HEAL	Hospice Educators Affirming Life
ASHA	Accredited Social Health Activists	HIPAA	Health Insurance Portability and Accountability Act
AVSM	Association of Voluntary Service Managers	HIT	Health Information Technology
BAME	black and minority ethnic groups	HITECH Act	Health Information Technology for Economic and Clinical Health Act
CAF	Charities Aid Foundation	HIV	human immunodeficiency virus
CBVs	community-based volunteers	HPC	Hospice and palliative care
CBWs	community-based workers	HPCO	Hospice Palliative Care Ontario
CCWs	community care workers	HPG	hospice and palliative care law
CHA	Under the Canada Health Act	HR	human resources
CHBC	community home based care	IiV	Investing in Volunteers
CHPCA	Canadian Hospice Palliative Care Association	IPM	Institute of Palliative Medicine
CHWs	community health workers	Khanya-aicdd	Khanya—African Institute for Community Driven Development
CMS	Centers for Medicare and Medicaid Services	LSGI	Local Self Government Institutions
CoPs	Conditions of Participation	LTC	long-term care
CPCA	Canadian Palliative Care Association (Later changed to CHPCA see above)	MCCM	Medicare Care Choices Model
CS	Caritas Socialis	NCD	non-communicable diseases
DOT	Directly Observed Therapy	NCVO	National Council for Voluntary Organisations
EAPC	European Association for Palliative Care	NGO	non-government organisation
ECEPT	Eastern and Central European Palliative Care Task Force	NHS	National Health Service
EHR	Electronic Health Record	NNPC	Neighbourhood Network in Palliative Care
EU	European Union	NPOs	non-profit organizations
FLSA	Federal Fair Labor Standards Act	NSW	New South Wales
German DRG	Diagnosis Related Groups	OAMGMAMR	Order of Nurses Midwives and Medical Assistants in Romania
GÖG/ÖBIG	GÖG/ÖBIG Gesundheit Österreich GmbH / Österreichisches		

ONS	Office for National Statistics	VNAs	Visiting Nurses Associations
OVC	other vulnerable children	VPTZ	Volunteers in Palliative Care The Netherlands
PaTz	Palliative Care in the Home situation	VTZ	Volunteers Terminal Care foundation
PC	palliative care	WPCA	Worldwide Palliative Care Alliance
PDV	Patient Data Vault	WHA	World Health Assembly
PHC	primary health care	WHAT	Hospice Voluntary Work as a Tool of Acceptance and Tolerance for People Leaving Penal Institutions
PLHIV	people living with human immunodeficiency virus	WHO	World Health Organization
RVH	Royal Victoria Hospital	WIIFM	What's In It For Me?
SIPC	Students in Palliative Care	WLRCT	wait-list randomised controlled trial
SOM	Services State Operations Manual		
SAVP	specialized palliative home care		
TB	tuberculosis		
UNV	United Nations Volunteers		

Chapter 1

The modern context of volunteering

Steven Howlett

Introduction

The idea for this book came when the editors produced the second edition of *Volunteers in hospice and palliative care: A resource for voluntary services managers* (Scott et al., 2009). That volume contained practitioner-written chapters on *how* to manage volunteers, offering a ‘state of the art’ view of good practice, but the volume also included an additional chapter on how volunteering for palliative care was organized in Kerala. The chapter gave a counterpoint perspective to organizing and involving communities in palliative care different from almost everything else in the book. Readers and reviewers picked up on this chapter praising how it piqued their interest to think about volunteering and palliative care in new and different ways. It was also evident that even since that book, a lot has changed in volunteering. Given the fast pace of change and interest volunteer-involving organizations have in encouraging community level—and led—participation, could a Kerala-like model show the way? Would that be possible within existing ‘ways of working’? We felt it was a good idea to review how palliative care involved volunteers and reflect on the changes that are happening from the perspective of practitioners and academics in different countries.

But of course it is too simple to believe that any model can be translated wholesale from one country to another. Volunteering is a product of different historical developments and cultural tradition—for example, a reading of Davis Smith’s tracking of voluntary action in the UK, takes the reader through the traditions of philanthropy and self-help covering the *noblesse oblige* ‘duty to the poor’ model while at the same time examining the bottom up self-help history of mutual aid essential to understand why voluntary action looks as it does in the UK today (Davis Smith, 1995). Salamon and Anheier (1998) broadened our understanding when they developed the social origins theory to explain how the prevailing attitudes of ruling classes to welfare expenditure

give a particular pattern of voluntary action. Their thinking helps explain why the United Kingdom (UK) is different from Asia and Asia from the Americas and so on. Rolling this forward, Colin Rochester (2013) used the UK to offer a well-crafted critique of how the distinctive nature of voluntary action has been captured and shaped by policy makers. In other words context matters, and if we are to learn new ways of working we need to consider why and how a particular approach works.

It is in this spirit that this book gathers accounts of volunteer involvement in hospice and palliative care across a range of countries and regions. As editors, we asked the contributing authors to tell us about volunteering in hospice and palliative care in their own country. We wanted, of course, some similarity in structure; we asked for a history of volunteering in hospice and palliative care—clearly these had to be snapshots. We asked for developments—what are the changes and trends, and importantly we asked the contributors (a mix of practitioners and academics) what they thought were the facilitators and barriers that were driving those trends. We wanted to be able to see how good ideas were sustained and to be helped to see if those ideas are transferable. In reading the accounts sent to us—we were struck by similarities and differences. The final chapter of this book looks to draw out what we saw as interesting themes. In asking the authors for their accounts we decided not to harmonize language unduly so where you notice differences in terms for volunteers, or community, or for people at the end of life, we ask you to read with that in mind. In some cases the authors tell us exactly why a term is chosen; in other cases it is up to us to reflect on how language results from context and tradition and how it may, in itself, influence current and future practice. The only rule we set was for the book to talk about ‘involving’ volunteers and avoid ‘using’ volunteers; though the reader will note that in Greg Schneider’s chapter the *Conditions of Participation* from the Department of Health and Human Services does just that.

This first chapter gives an overview of the modern context of volunteering by looking at trends and research about volunteering in general to offer a context for the chapters that follow. So much has been written about volunteering and its reach can be seen almost anywhere. For example, ask what seems like a basic question: ‘what motivates people to volunteer?’ (a key concern for all the authors in this volume) and you will soon find more studies than you could comfortably read and assimilate without it becoming a major study. To get a working knowledge a good start would be classic studies by Clary et al. (1992, 1996, 1998) outlining the Functions Index which aims to identify the psychological needs that motivate volunteers and, in turn, should help volunteer managers attract and keep volunteers by fulfilling those needs. After that it really depends on what specialized area is of interest— for example the role altruism plays in

decisions to volunteer (see Burns et al., 2006)—or the social and political context that motivates students to volunteer. For example, see Hustinx et al. (2010) for a study comparing motivations across six countries. Young people, after all, will be the volunteers of the future and because we see that in the UK the trend in declining number of hours given to regular volunteering is reversed in the 16–24-year-old age group, according to the Office for National Statistics (ONS, 2017a) we may want to know more about how to engage the young. Or maybe your organization still sees older volunteers as your key source of volunteers. If so, then start with Okun et al., (1998) to tease out the different motives for older volunteers. We could go on. If you are asking ‘what about hospice and palliative care volunteers?’, you need only search for the works of Stephen Claxton-Oldfield whose account of volunteering in Canada appears in this volume. And yet, for all the studies, one report in the UK quoted a practicing volunteer manager as commenting: ‘Motivation is one of the most over-researched topics [but] none of the research really gives a practitioner anything valuable because everyone’s different’ (quoted in Saxton et al., 2015: 35).

As people with a keen interest and some involvement in researching volunteering we would argue that this perhaps goes too far and that there is much value in the insights research brings to all aspects of volunteering, not least motivation. But we also note that the ever closer examination by volunteering researchers into narrower and narrower specialities, in ever expanding sectors, and into different organizations maybe leaves those readers frustrated who want a more holistic view. This is, in turn, not to overlook the work of organizations and publications that specifically look to present readable, practice-focussed work—such as the already quoted. (NFP Synergy Reports, the work of organizations like the Institute for Volunteering Research in the UK or e-volunteerism in the United States). These, and others, present research-based ideas for discussion in such a way that practitioners and academics can engage with each other. To those we hope to add this book. It can be read as accounts and stories (indeed readers will see how powerfully volunteers tell their own stories in Chapter 15 and in the stories of Compassionate Neighbour volunteers in Chapter 14 by Sallnow and Richardson). In the final chapter (Chapter 16) we summarize some of the points that are worthy of comparing and contrasting when thinking in terms of community development as much as volunteer management development, about the pros and cons of national structures for standards and just how important is it that there is some government-led policy backdrop acknowledging the work of volunteers?

The rest of this chapter offers a necessarily short background look at what we know about the people who volunteer, about the organizations they participate in, and how governments are shaping the volunteering environment. It draws

on UK data to show what trends are seemingly emerging and it errs towards volunteering in general to hopefully set questions in mind for the reader for the subsequent chapters.

People who volunteer

Knowing how many people volunteer always presents some difficulties because figures derived from surveys depend on how the survey was constructed and conducted; we know that how a question on volunteering is phrased can dramatically alter the response (Lyons et al., 1998). Comparisons over time *within* countries often need explanations and caveats to take account of different questions asked and different survey methodologies and attempts at international comparisons merely magnify the challenges (Rochester et al., 2012). At the time of writing up to date figures appeared in the Charities Aid Foundation (CAF) World Giving Index for 2016. This covers both the giving of time and money. The challenge of interpreting figures is clear immediately because the report gives figures for ‘helping a stranger’ and ‘volunteering time’. We may argue that the former is part of the latter. Even taking the latter as a formal action performed through an organization the global league table makes us pause; Turkmenistan has top position which it had held from 2011 until the 2015. The reason given for its slipping from top spot in 2015 was that ‘Saturday Subbotniks’ had been cancelled. Subbotniks were times when people were ‘expected’ to volunteer during the Soviet era (Davis Smith, 2001 references Subbotniks in his review of the relationship between volunteering, the state, and democracy). That is to say, there is a question about how voluntary the volunteering was. The country’s return to the top of the rankings may show that there is a spirit of volunteering separate from the ‘coercive’ nature of Subbotniks. It certainly shows that measuring volunteering is not easy. Nevertheless, the CAF report makes some general comments on global volunteering that do help to set a broad picture. It notes that since 2014 there has been a small increase in the proportion of people volunteering their time—from 21.0–21.6 per cent, and that this is an increase from the 2011 benchmark which was 18.7 per cent (CAF, 2016).

Separating out data for the UK in the report shows that 33 per cent of respondents saying they volunteer time, and, as changes over the previous year were only noted where it was a rise or fall of more than three percentage points, we may conclude that the rate of volunteering in the UK remained broadly steady. Figures from the UK Government Community Life survey (noted by the Institute for Volunteering Research as the best source of data) for 2015–16 indicated that 41 per cent of respondents in England volunteered formally

at least once in the previous year. It also noted that 27 per cent were 'regular volunteers', that is they said took part at least once a month. Crucially, the figures show no significant changes, which were 42 per cent for all volunteers and 27 per cent for regular volunteers (Cabinet Office, 2016).

The point here is that though the totals may be different from the CAF analysis, *the trend* is the same, broadly speaking the same number of people participate. This is echoed in a study of a number of volunteering surveys in the UK by Staetsky and Mohan (2011). While this may be disappointing for policy makers wanting to encourage more active participation in community life, it does suggest that roughly the same number of people are there and ready to help. A steady number of people volunteering must be good news. But, despite what the volunteer manager quoted above noted, there are developing trends within active volunteers that managers should look to research to explain. These trends will probably alter from place to place and similarities and differences will be evident as the authors of the other chapters describe from their own experience of working with volunteers in hospice and palliative care in different countries. Volunteering data collection, however, is variable. Canada, the US, and the UK have traditions of national surveys of volunteering. When it comes to identifying volunteering in hospice and palliative care it is much harder. While a number of countries collect national hospice and palliative care volunteering data on a regular basis, (see Austria, Chapter 4) at this point in time the UK does not. Some, therefore, may not have national figures to frame their understanding of their own work, but it is noticeable that there is only fleeting worry that palliative care struggles to find volunteers. Scott (Chapter 3) makes the point that despite changes in volunteering in hospices and palliative care services in the UK, by and large attracting volunteers is not problematic. Most of the accounts given in this work have authors identifying fairly stable 'types' of volunteers in terms of age and gender; Claxton-Oldfield notes a 'typical' volunteer as female, white, middle-aged (Chapter 8), or older and not in paid employment or retired. It is the exceptions to this that are notable; for example Palleri and Sallnow specifically note the younger age profile of volunteers within one neighbourhood scheme in India compared to those in other parts of the country (Chapter 12).

Taking this 'steady-state' of volunteering as the backdrop, can we discern trends within it? Using the example of the UK and looking across several sources in the UK we can see, again, a reasonably consistent picture. There is no discernable gender difference between men and women for formal volunteering, but with differences in what each do; women are more likely to provide caring and men representation roles (National Council for Voluntary Organisations (NCVO), 2017). By age group the highest rates of regular volunteering (at least

once a month) are in the age groups 16–25 and 65–74 years, the lowest is in the 25–34 years range (NCVO, 2017), figures from the following year show this age difference as even more pronounced. The Office of National Statistics, reporting on time spent volunteering in the UK, finds that between 2012 and 2015 volunteers gave 7 per cent less time to communities over the period, and, when a notional wage is given to this it equates to a ‘loss’ of more than £1 billion. This research shows that—in line with these figures—the 16–24 year group (note the slightly different grouping) increased the time they gave while for the 25–34 year group time given fell (ONS, 2017a). Analysis by time given also shows that although participation rates between sexes is the same, women gave an average 1.50 hours a week in 2015 while for men it was 1.19 hours. The picture seems mixed, but again the message is ‘broadly stable’. What this chapter does is only to give an illustrative picture for the UK of formal volunteering (through an organization), but the chapters of this book invite comparison of what trends look like and mean in the context of hospice and palliative care volunteering in each country.

The research shows, therefore, that overall volunteer numbers are holding up. Does research indicate that these volunteers are participating for different reasons? We have noted that there is a wealth of research on motivations and a practitioner’s more sceptical view of how that research helps. Certainly within the following chapters motivation is a key theme. The volunteers in Sallnow and Richardson (Chapter 14) talk of having a chance to exercise compassion and deepen feelings of community belonging; themes echoed in the volunteer stories in Chapter 15. Kiyange (Chapter 11) in an overview of palliative care across many African countries also noted themes of compassion built out of cultural traditions of community care. But other motivations are evident too—of how volunteering can lead to paid work, and how in areas of poverty payment of a stipend encouraged involvement. While these varying motivations could underline the previous comment that motivations are very individual and so studies can tell us little, we can also reflect and echo more broadly, understanding changing volunteer motivations.

Motivations can be considered from a psychological perspective or a sociological one. The former asks what needs someone is looking to satisfy through volunteering, the latter looks at how people contextualize their involvement (Rochester et al., 2012). The work of Clary and colleagues (1992, 1996, 1998) is framed in psychological thinking with motivation translated as the need to, for example express values, or acquire experience, or to feel that one is giving something back to the community. It has proved to be a compelling model and research often follows the idea of categorizing volunteer ‘need’ and matching it to volunteer task (for example, see research in event volunteering by Treuren,

2013). Hustinx and colleagues (2010) theorize the sociological perspective in their work on reflexive volunteering in young people. They argue that volunteering is seen as a self-project where volunteering is part of a person's identity. The work of the Pathways to Participation project in the UK can be seen in this light. The volunteers interviewed tell their story, what volunteering means to them, and how it is part of their life (Ellis Paine, 2015). Conclusions drawn from the interviews include that 'There is a need to move beyond explanations of why people volunteer that focus on asking their motivations, and of how people volunteer that focus on isolated volunteering activities' (2015: 1). Chapter 15 of volunteer stories in this volume can be read with this in mind. We can draw out motivations but we can also see how the stories reflect what volunteering means to the volunteer. Perhaps this suggests that the modern context of volunteering is one in which the practitioner needs to be able to synthesize both these views, by looking more holistically at motivations. Studies like 'Pathways to Participation' become as important as volunteer surveys and it as well to be careful that we do not assume survey results carry more weight. One survey listed 10 motivations and asked volunteer managers 'Do you think any of these have become more important to volunteers over the last five years?'. Eighty-one per cent of managers list 'Improving their CVs' as what they saw as an increased motivation to volunteer which 72 per cent identifying 'Developing new skill' and 53 per cent 'Developing existing skills' (Saxton et al., 2015). In fourth place was 'Giving some back' identified by 33 per cent. Religious belief was identified by just two percent even though other surveys indicate that being actively religious has a significant influence on the propensity to volunteer (Low et al., 2007). Perhaps because the survey captured perceptions it may be that these more skills-development motivations are increasing whereas the others remain important but are just not *seen* as becoming more important. Nevertheless, this does seem to resonate with the idea that motivations to volunteer are being driven by more instrumental reasons and that if organizations are to recruit more people their message needs to be broadcast on the What's In It For Me (WIIFM). Underlining this is the idea that '[T]here is little doubt that the current age of austerity, together with more long-standing changes in access to higher education and the competitiveness and composition of the job market, has pushed the salience of employability to the fore' (Saxton et al., 2015: 38).

Motivations then may vary, but what we see here is a weaving of the twin ideas of volunteering being part of a person's identity and for volunteering to offer the volunteer something they can use in other facets of their life. The two are not at all mutually exclusive and how we develop and support volunteering needs an understanding of how these two aspects combine. Back in 1996 Davis Smith

noted Peter Drucker's assessment of volunteers transition from well-meaning amateur to a trained, professional member of staff who would expect responsibility, a part in decision making, opportunities to advance, and lots of training (Davis Smith, 1996). Such a model could clearly help volunteers who are looking for experience and transferable skills. It can also help volunteers feel that their time is being well used and appreciated. And yet, there is also a warning that the 'paid work without pay' model can too easily slip into volunteering being managed in such a way it can be less appealing (Rochester, 2013).

Organizations involving volunteers

Having considered who volunteers, we now turn to how volunteers are supported and managed. Much of the research on volunteer motivation emphasizes that the practical application is that by identifying what volunteers want, organizations that meet those motivational needs can expect to have satisfied volunteers. But the task of managing volunteers has more to it than that. Indeed when Drucker suggested that volunteers are trained, professional members of staff (albeit unpaid) there is an implication that the management of those volunteers is equally professional and organized. Volunteers need skilled managers and there continues to be a call that volunteer management should be a profession in itself in the UK (Howlett, 2010; Payne and Morris, Chapter 2). It is not an unreasonable call once the breadth of skills needed to manage an unpaid workforce is appreciated. The chapters in this volume on volunteering in hospice and palliative care give a clear signal of the place of the volunteer manager in successful volunteering; Huntir is in no doubt that the success of palliative care volunteering in Australia is underpinned by organizational support for volunteers, by the skills of volunteer managers and by the inclusion of volunteers in aspects of service management. If Drucker is right and 'training, training and more training' is crucial (Quoted in Davis Smith, 1996: 192) then our contributors have a wealth of knowledge to share.

However, research and writings on managing volunteers urges caution. Rochester et al. (2012) reviewed research on the formalization of volunteering arguing that volunteer management was increasingly adopting the techniques of private and public sector management and that this need not be accepted as an inevitable norm. The theme was taken up by Saxton et al. (2015) in their review of volunteering and volunteer management. They argued that volunteering was being held back by an over acceptance of volunteering as analogous to HR management. Quoting practicing managers they argued that 'fixing systems and processes' was assuming more importance than dealing with people. Even so the authors argue that the HR model

‘[I]s not without valuable lessons: supervision and support; the need to consult and set objective; proper legal oversight to protect both parties.’ (Saxton et al., 2015: 74).

The argument for well thought out management is a strong one. The idea that volunteers are not passive recipients of tasks given to them by organizations needing ‘an extra pair of hands’ is not new; back in 1996 Davis Smith noted that there was already a growing sense that volunteers were ‘voluntary not amateur’, and that they needed supportive and professional management to not only fulfil their tasks for the organization but also because they wanted a meaningful role that could be seen to be making a difference. In this sense volunteering is amenable to and in need of ‘management’. Indeed while researching the challenges of volunteer management in health care in the United States of America, Rogers et al. (2013) go on to extent the idea that volunteering should not only be part of an Human Resources (HR) function, but a ‘strategic’ HR function to better align volunteering to organizational needs and that performance indicators for volunteering needed to be developed. Their argument for management is compelling (what is the best way to ensure your new volunteer doesn’t come back for a second day? Tell them to ‘sit in the corner and have a cup of tea while we think of something for you to do’) but Davis Smith (1996) was also keen to point out that the advance of ‘the managerialists’ was being resisted, not least by those who saw ‘the workplace’ model as damaging to that other concept that needs scare quotes—‘the spirit of volunteering’. That debate, as we have noted, has been fleshed out and argued thoroughly by Colin Rochester arguing that conceptualizing, and organizing volunteering, as if it is an economic activity—paid work without the pay—may not always be helpful (Rochester, 2013; Rochester et al., 2012). For sure, studies tell us that volunteers want development, skills, to know what they need to do when, and to know where it is possible to use their own initiative. But at the same time we should not ignore that the ‘management’ school of voluntary action is counter-poised by the organic participatory role (Zimmeck, 2001). By concentrating on training, organization, management, and so forth our authors may simply be in the thrall of the management school. And yet, many are talking about how the ‘service’ the volunteers provide is being extended out of ‘buildings’ (hospices and hospitals) and into homes and the community, and explicitly drawing on community development models to grow these activities (for example, see especially Goossensen and Somsen, Chapter 5; Sallnow and Richardson, Chapter 14, in this volume). If we are to consider the modern context of volunteering we need to ensure we are not entirely trapped by notions derived from management thinking. Brudney and Meijs (2014) approach the issue by arguing that where volunteering replicates paid work an HR analogous model is logical, but where

the volunteer role is less defined (their research was on volunteers in social work), managers need to be more fluid in their approach.

The debate may seem easier at the extremes—a volunteer giving complex legal advice for example may need regular updating for, de-briefing on cases, supervision on performance, and so on: while volunteers in a hobby club—which is more like Rochester’s notion of volunteering as a convivial activity—may need a minimum of organization. But the middle ground is trickier. Read the stories of the volunteers in this volume and you may see people who just want to help and not be subject to a management control, but in the chapters you will also read of roles where specialism is key and management support needed. All of the chapters in this volume have easily identifiable management models and structures and readers will note just how formal some of them are. In other places there are spaces evident for volunteer-led services, initiative, and voice. We asked contributors to identify what works for their contexts and perhaps it is evident that managerial discourse rolls on. And yet, in places—very evidently in the volunteer stories—we still see the importance of that elusive ‘spirit of volunteering’.

The policy-makers

We cannot consider the modern context of volunteering without looking at how some of the issues already noted are driven by influences outside volunteer-involving organizations. We often think of volunteering as part of the third sector, and that by implication is not part of the state or market. We would be wrong of course not to think wider than that—much volunteering happens in the public sector. If we take the UK again as an example, volunteers acting within school governance roles number somewhere about 300,000. Although methods of calculating the value of volunteering vary, the Office for National Statistics in the UK put the figure at £22.6 bn, or approximately 1.2 per cent of GDP (ONS, 2017b). Given that scale of contribution it is little surprise that policy makers are keen to encourage more participation. But it is not only the economic contribution which attracts attention, the social benefits of participation are also hugely attractive. Haß and Serrano-Verlade (2015) note that several European countries have instigated national volunteer service programmes largely because alongside the economic argument ‘[V]olunteering develops forms of civic engagement and solidarity that are vital to the integration of modern societies’ (p. 1720). For Ellis Paine and Hill (2016) the benefit is threefold—the distinctive contribution of volunteers, the democratizing of services, and the cost effectiveness. For policy makers volunteering offers a win-win—encouraging participation helps to fix broken parts of society and offers a huge resource.

In the UK we can see the interest and influence of government directly on volunteering. Government programmes start most obviously in the 1970s with the Good Neighbour Campaign (Davis Smith, 1998), since then there have been numerous others. Young people have been catered for by the Millennium Volunteers programme under Labour followed by the Conservative government version of a National Citizen Service. There have at various times been programmes focussed on older volunteers and to encourage employee volunteering. So, on the one hand government have been encouraging volunteering, it seems, because it is the right thing to do. Any of the government-sponsored programmes can fit nicely into wider aims to characterize what a participatory society is. More recently, this took the form of former Conservative Leader and Prime Minister David Cameron's idea of 'The Big Society'. On relinquishing the Prime Ministership to Theresa May, the notion converted into the idea of the 'Shared Society'. Though in truth any of these concepts lack a core idea that is easily understood. Little wonder then that too often the ideas lose traction and volunteering is cast more in its economic possibility than its participatory one. Sir Stuart Etherington, Chief Executive of the NCVO writing on the year ahead for the voluntary sector in January 2017 noted 'It was saddening to see the former prime minister's theme of a big society lost momentum and became derided as simply a cover for cuts' (Etherington, 2017: 3). And there lies a problem: government wants to encourage volunteering, and even puts in place programmes for it, but the lure of a 'free resource' means volunteering is often seen as cover for ever more needs that government struggles to meet. Again reading through the contributions to this book and you may be struck by how many hospice and palliative care services are expanding to meet new demands which are often age related, for example dementia. You may also be struck by how the funding for this comes through one government department or another. Reading the United Nations Volunteers (UNV) *State of the Worlds Volunteerism Report* you will be left in no doubt of the power of volunteering to shape governance (UNV, 2015: xiv) and reading the chapters in this book you will see how hospice and palliative care volunteering too is centred around participation and activism. But it is also clearly about service and how to manage those services.

The context of volunteering for government is how to harness volunteer energy, and that too is about priorities. The future of the National Citizen Service mentioned has recently been questioned by the parliamentary committee that scrutinizes public expenditure as too expensive (BBC, 2017). And yet we know that one of the key indicators of likelihood to volunteer is having done it before (Musick and Wilson, 2008). In other words we know that encouraging young people to be involved in voluntary activity is likely to mean more will be

volunteers in the future; we can effectively look forward to future savings (the economic model) and participation will help with citizen education. And yet, the cost now may be too great. The modern context of volunteering could be that we are not looking far enough into the future.

Payne and Morris in Chapter 2 note that the World Health Assembly in 2014 issued a resolution to integrate palliative care into national health care systems. The chapters in this book make reference to the history of hospice and palliative care from, in most cases, its voluntary roots. And while that will probably remain, drawing care into national health systems will most likely have the subsequent effect of increasing rules and procedures to respond to oversight by statutory organizations. Again not necessarily a bad thing, and in many cases it may bring additional funding. The likelihood is however, that this will increase formalization which Payne and Morris note. In such circumstances the criticism mentioned earlier that managers look to systems and overlook people seems an inevitable result of hospice and palliative care being drawn into national health care systems. Of course it need not be inevitable that it happens without sensitivity and oversight. We will see in some of the following chapters that volunteering in hospices and palliative care and the participation of volunteers still has themes of activism of doing something because it is needed irrespective of whether governments are addressing problems. It retains notions of developing services where there is need as well as within institutions of care and it still draws on the willingness of people to work without pay to give something back to the communities in which they live.

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