

Glasgow End of Life Studies Group

Global Interventions at the End of Life – an interdisciplinary investigation

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Transcript

Good evening everybody and thank you to Sir Ken for those words of introduction. I would also like to thank the Congress and the University of Glasgow for helping to make this session possible and I'd also like to welcome some invited guests who've come along to join us this evening for this lecture.

I think it was in 1992 that I first came with Sam (Professor Sam Ahmedzai) to Glasgow for what was the second meeting of the Palliative Care Research Forum. There were 32 people there and that was an improvement on the 17 that had met the previous year in Cardiff. By 1995 we were having a meeting of the Palliative Care Research Forum and the Association of Palliative Medicine at Durham University, Eduardo Bruera was one of the speakers, and over dinner a plan was cooked up to bring together the PCRF (as it then was), the APM and also the Palliative Care Nursing Association and they would all work together to produce something called the Palliative Care Congress which has gone on from there every 2 years, this being the 11th, so some of its history certainly goes back to Glasgow in the early 1990s.

In preparing for tonight, I was thinking back over those years and thinking a little bit about my own particular areas of interest that I've been able to pursue in that time. I have to say that some of them have been very much encouraged by Sam in the early days, really focussing on 4 themes that have interested me: Policy and Evaluation and increasingly Implementation of Hospice and Palliative Care Programmes; work around the Global Development of Palliative Care and attempts to map and to some extent rank that development. I've also had an interest in the Sociology and Anthropology of Death and Dying in that time and a particular focus on the History of Hospice Palliative Care and related movements. In the last 18 months I've been freed from fascinating but onerous duties as the Director of the University of Glasgow's Dumfries campus and I've had a chance to get back to some of this work in earnest. Most recently I've been working with the Scottish Government for the preparation of its Strategic Framework for Action which will shape the direction of Palliative and End of Life care over the next 5

Glasgow End of Life Studies Group

years here in Scotland and also doing some particular studies locally on the situation of patients in hospital and their likelihood of death within a year in Scotland and this has been some work that has caused a lot of interest, not only locally but further afield, where we've showed that in effect and now twice in two separate studies, that on any given day in Scotland one-third of patients in hospital are in the last year of life. It's a great opportunity for some of this advocacy and focus on End of Life planning to be taken up if these patients can be identified.

Though this has been some of the work that I've been doing focussed around these different themes I got these books out on my kitchen table a couple of days ago. I was slightly tired when I laid them all out and some of them I'd forgotten about and probably you've forgotten about most of them. This one's particularly important to me. I've just finished this book and it's on the History of Palliative Medicine from the 19th century, essentially framing the 100 years from 1887 when William Munk, pictured here, published his book on Easeful Death, called Euthanasia using that older meaning of that term from 1887 and William Munk to 1987 and the creation of the Palliative Medicine speciality in Britain. This is essentially the theme of this new book which is coming out in September / October of this year.

All of these interests in a sense have shaped where we've got to with this new project 'Global Interventions at the End of Life' and I know that some of you have been making notes and wanting to take down details of this, please don't and refrain from that, just enjoy the lecture because at the end you're going to be given, by members of our team who I think are out there somewhere – can you wave their hands – yes some of them are there – given a copy of this remarkable origami that we've produced, especially for you that captures the whole of this lecture just in a few small sheets of paper. So make sure you go home with one of these.

So, Global Interventions at the End of Life. It's a study funded by the Wellcome Trust under its Investigator Scheme (I've been lucky enough to get a Wellcome Trust Investigator Award) and it's really exploring these three major questions. We're interested in:

Why, and how and with what consequences a field of End of Life Care has emerged around the world in recent decades.

Glasgow End of Life Studies Group

We're particularly interested in how End of Life Interventions of various kinds are being formulated and delivered in different settings and with different kinds of outcomes and implications.

What we're trying to do ultimately is to somehow get above this whole emergence of a global field and as social scientists frame the issue in perhaps some new ways, and bring some new concepts and ideas to the table that might over time lead to greater efficacy in this work and also contribute to the sustainability of End of Life Care programmes and interventions in the future, because as we are going to see, the demand for these kinds of interventions is going to grow very significantly in the coming decades.

So I'm lucky enough to have a great team of colleagues to work with on this project. This was us just one year ago when our group formed – the first day of our study on the 1st March 2015. On the left is Shahaduz Zaman who is a medically qualified anthropologist with a particular interest in Global Health, originally from Bangladesh. Then myself, then Catriona Forrest who is from this part of the world, from Glasgow, our Public Engagement Officer who has been working with us from the beginning of the project looking at ways to engage wider audiences in the work that we're doing using a variety of media which I'll explore more later on. And then Hamilton Inbadas from Tamil Nadu, an ordained priest in the Church of South India, trained in ethics and theology and working with us on our team.

So that was us a year ago and now we've expanded a little bit and we've been able to appoint a new lecturer to work with us, Naomi Richards who is pictured in the middle at the top there and we've also engaged a lecturer in Public Health, a social scientist Sandy Whitelaw at the bottom there. Both of these people now working with us very closely as our project unfolds.

I thought it might be helpful to try to get some sense of the scale of the questions that we're trying to address by looking at this diagram that was produced by the Wellcome Trust a couple of years ago and it was an attempt to classify, not just the numbers of people who died in the course of the whole of the 20th century but also the major causes of death and you can see them outlined there in the dense colours: non communicable diseases, death caused by human interventions of various kinds, war, conflict and so on. Cancer rather a smaller a figure in relation to the total and infectious disease a massive number. My purpose here isn't to go through that in detail but to raise a question that arises from it: this figure of 5.5 billion people who died in the whole of the 20th century

Glasgow End of Life Studies Group

as far as we are able to estimate is in fact a figure which is lower than the current population of the world. You might say that's comparing an apple with an orange but I think it gives us some sense of the scale of the issue when we're looking at human mortality and interventions at the End of Life that we are going to face in the coming decades.

There are more people alive today in the world than died in the entire 20th century. So this is something of the scale of the issue that we're trying to look at. We know at the moment there are something like 56 million deaths in the world occurring every year, 85% of these in the developing countries but most of the discussion about the manner of the deaths of those people and how they are cared for focusses on the 15% who die in the richer parts of the world.

There are sketchy estimates of what these figures might turn into in the future, but we've seen an estimate that by 2050 it could be something like 90 million deaths occurring in the world every year. This is a phenomenon associated with global population growth that's driven not by an increase in the birth rate but rather the increase in population that is driven by global ageing. It's not often recognised that the global birth rate has been declining since the early 1980s. It's not more children being born that's expanding the population it's all of us living longer, not just in the West but in many other parts of the world as well.

So there are many, many implications here for thinking about End of Life issues in this global context and then within that there are new and unpredictable challenges that result from new infectious diseases – we've seen the impact in the 20th century of HIV and AIDS and multi drug resistant TB. There are also now as we're living throughout this moment, complex humanitarian emergencies which are also adding to the figures of numbers of people dying in different circumstances all around the world. But if you take that 90 million figure and you do a quick calculus based on the number of people who are affected by the death of any one person then we could be looking by the second half of this century at some half a billion people each year who experience the death of someone close to them, whatever the NICE term is for that: 'someone important to them' - it's such a touching and heart-warming phrase isn't it? So these are some of the trends and then the challenges that flow from that. We're concerned about the numbers growing but we're also concerned about, if you like, the 'global prepared-ness' for this. To what extent is the world, the global society and all of the communities within that

Glasgow End of Life Studies Group

society engaged with the challenge that lies ahead? Not only as in some communities people become more enabled to deal with these situations but recognising also that in other places and in other communities they become more impoverished in their ability to respond to these questions.

Part of the starting point for our project is that in this context there is really no consensus around how we should die, the circumstances in which care should be delivered, what is optimal and what is desirable. We've seen from the previous presentation that in the country that ranks as having the best End of Life care in the world there is precious little evidence to support what is done and there is a lack of consensus about what should be done. We're trying to engage in those questions not just in the context of England and NICE but in the context of global society. So we're asking questions about the complexity of this and the scale of it and what the global future of dying is going to look like. And one of the questions that's in my mind as well in terms of the demographics is just as with the notion of 'peak oil', that point in the history of the world when oil production reaches its maximum or the concept of 'peak baby' that point in the history of the world where more children were born in a single year than ever before or subsequently has occurred and that was in fact 1982 – when we might reach 'peak dying' and what will the consequences of that be for global society when it occurs.

We think that there is a need in looking at these questions, yes to gather more evidence, yes to do more research and empirical enquiry but perhaps much more importantly to bring together to the table new perspectives, new ways of thinking and in particular new theoretical perspectives or other theoretical perspectives from elsewhere that might help us to somehow tease out the complexities of these questions and the responses that we will need to make in the global context. These are just 3 of those perspectives that we've been using in the last year in our own project to try and find some new ways into these questions. Globalisation is probably an obvious one to start with, that whole notion of globalisation as a stretching process in which individuals of different backgrounds and cultures interact with each other in new ways across spheres of life and perhaps more intensively than at any point before in our history, much of this fed by social media but also by global and international travel and the flows of labour and markets and skills and so on.

Glasgow End of Life Studies Group

There's a lot of debate about globalisation; there are those who praise it for its benefits and the sense of progress that it brings to the world. There are others of course who are very critical of the forces of globalisation and are seen as being exploitative of the most poor and vulnerable people in society, seen as arms of more imperialist approaches and global governance. But the whole idea of globalisation has forced us to stop thinking about national character as somehow the defining principle of how we make sense of peoples of different jurisdictions and countries and has turned our attention much more to issues about identity, about gender, about the politics of these things, about ethnicity and within that we see the role of cultural champions of religious and other kinds of new social movements playing a very strong part in the way in which the sense of globalisation affecting us at a very personal and individual level is being played out. So inevitably we have to, in thinking about the global challenges at End of Life care we think we need to look at these theories and ideas about globalisation to see to what extent we can use these to make sense of what's being observed and ask the question are we encountering a kind of globalisation of dying and if that is the case is that something to be celebrated, is it something positive or does it contain inherent risks and problems and difficulties as a social process.

Added to that there's a developing field in policy studies, known as policy transfer, sometimes referred to policy mobilities. Essentially it's asking the question what happens when you take one policy, intervention or approach developed in a particular setting and seek to implement it somewhere else in order to achieve similar goals. This whole idea of transferring ideas, policies and strategies from one location to another we think are very very relevant to an understanding of the global development of End of Life care and palliative care in particular – ideas about it coming from hospice. We often read in the international palliative care literature about the importance of finding models that work and then 'rolling them out' internationally and globally. The policy transfer literature, the frame that you get when you start to use globalisation as a theme to look at these issues, really starts to question the value of that approach and the wisdom of seeking with enthusiasm and passion to roll out things that have worked in one place, or as we have seen with the Liverpool Care Pathway, haven't worked in one place, to other settings. I'll come onto this later, but we're interested in our study in the LCP not so much for an understanding of what went wrong in Britain though I think that that is badly needed and is yet to be done, but I think our focus will be on the 20 or more countries to which the LCP was 'rolled out' - in this language - and to which there has

Glasgow End of Life Studies Group

been so far, as far as I'm aware (but please correct me if this isn't the case) been any commentary. So we are dealing here with a global set of challenges around the ways in which policies, strategies, innovations roll out and transfer from one location to another and we think this is a very fruitful line of enquiry for us.

But perhaps the most exciting for me intellectually of the approaches which we've been exploring came very much from Zaman's ideas and thinking, draws on the work of Dipesh Chakrabarty, a very notable Bengali scholar, whose work in the field of post-colonial studies sometimes referred to as 'Subaltern Studies', and we learned about this from Zaman and he's learned about it from Dipesh himself who he's in regular contact with and it's captured I think in this wonderful metaphor this notion of 'the waiting room of history'. What are we talking about here? Well what Dipesh is really saying is that the underlying assumption that exists in the global context of making comparisons between the rich world and the poor world, or the developing and the developed world, is that somehow the developing world is in the process of 'catching up' with what has already been achieved elsewhere. He describes this as a narrative of transition that all developing countries are seeking to pass through and it's one in which the archetype of what is to be achieved is to be defined in terms of European values and the values of the enlightenment. These are the archetypes that other less developed nations are seeking to arrive at and this could be democracy, it could be prosperity, universal suffrage, a whole range of ideas that are promulgated within the European enlightenment project which others now are seeking to achieve and are in the 'waiting room of history' waiting for this to happen. In that narrative therefore, the situation of the developing world with low and middle income countries where as you will remember 85% of all the world's deaths takes place is one that is characterised by concepts of lack, of absence, of incompleteness. You'll often hear it at palliative care meetings and I've certainly heard it when you say to somebody or you hear it said 'do you have opioid availability in your country?' and the person says 'not yet'. So it's this notion that we've yet to arrive somewhere that you have already arrived at. Now we think that this is very very fruitful terrain for exploring attempts to globalise specialised palliative care and the beliefs, ideologies and practices that exist within the palliative care movement into settings around the world. And what Chakrabarty is really pointing to here is that the relationship of transfer is one that needs to be seen in this kind of light but needs to be added to with the concept of translation – what happens when these ideas from the European archetype *transfer*, they are also *translated* in the process they are changed in

Glasgow End of Life Studies Group

the process and there is the potential for those ideas to come back and to travel in the opposite direction. And these are some of the themes that we are trying to explore in our work.

And what we've decided to do is to focus down on 'interventions' in order to do this. We're asking how End of Life interventions are developed, implemented, assessed and with what consequences. We're doing this globally and in particular what we're trying to do is to build a typology of interventions. Now you'll see in a moment that this typology is very comprehensive. It's not just about things to do with care, it's an attempt to look at all of the ways in which, as human beings in different societies and contexts we make responses in an organised way to End of Life issues. So we're trying to build a typology of interventions, a typology or taxonomy, and then what we're trying to do within that is to select interesting examples for more in depth review and reflection.

So our definition of an 'intervention' is currently, and this is a work in progress: 'interventions are organised responses to End of Life issues'. And we're using that term 'organised' quite carefully because as you'll see in a moment, it can be organised in a very strong sense in the terms of something that's recognised in law or in policy or in some kind of mandate, but we are also interested in it in a kind of softer or weaker sense where we're referring to something that's organised in the sense that it's part of a framework of belief or action which might be quite individual or personal or local in character. We're trying to see interventions very very broadly in this way. And what we've decided to do is to look at two dimensions of these End of Life interventions and we call this the *focus* and the *locus*. What we mean by the focus of interventions is the character of something, of some organised response to an End of Life issue. So this is about defining the elements that are within the intervention – seen as a set of objects to which it's addressed and the purpose of intervening, we're trying to conceptualise our language here about the content, the orientation, the qualities of the intervention. It can include the goals, the ambitions of those who construct and deploy the intervention. It can involve an exploration of its culture, its character, its make-up. Listening to the story of the LCP you can't but help acknowledge the importance of those kinds of dimensions in making sense of what happened when the LCP as an End of Life intervention was introduced. But we feel that those dimensions of the focus are often overlooked. We go straight to evidence of efficacy but we don't properly tease out some of these other more subtle and dynamic characteristics of the intervention. We add to that the locus and by this we mean the geographical scope and spread of the

Glasgow End of Life Studies Group

intervention, so we're particularly interested in our study in interventions that move around between different jurisdictions, different parts of the world or different settings. And we're especially interested in the way in which the focus of an intervention might change when locus is also changed.

So we're talking about locus and focus, we're also talking about transfer and translation. Tony Walter, the sociologist once told me 'people can't make sense of anything more than a box with four things in it' so we're trying to limit our conceptualisation here a little bit. Locus and focus, transfer and translation. But we had to disappoint Tony a little bit when we came up with the ten categories of intervention. I have to say I struggle to remember them all myself, but...

This has been the product of a lot of searching and discussion and reading and debate between us and we tried to identify a comprehensive range of categories that you could use to describe organised responses to End of Life issues – interventions of some kind. Some of these are very obvious in character, they relate to particular types of clinical intervention or to particular sorts of services, they relate to specific policies around End of Life care. But we've also added in other things. We think that education for example is an intervention, we think that research itself is an intervention and we need to be more reflexive in our thinking about the role that research plays in not only understanding the world but also in changing it. And we've also started to identify some kinds of interventions that may not immediately appear as interventions.

And it was partly being challenged by the Wellcome Trust as I was in the process of applying for this grant. Part of the process involved an interview and I remember being asked by a social anthropologist 'when is an intervention not an intervention - what would you define out of being an intervention?' And so we started to think about it for example here in the bottom right category 'self-determined interventions' - things that individuals might engage in, actions, decisions, choices made by individuals to engage in or indeed to refrain from. Something that has implications for them at the end of their lives or the end of the life of another.

So just to give that just a little more detailing – self-determining interventions could include but not be limited to, voluntary refusal of food and fluids, rational suicide, assisting of suicide, mercy killing. We're also inspired by our colleagues in the University of Navarra, at the ATLANTES project, led by Professor Carlos Centeno. They've got a theme running around the 'intangibles' of palliative care and we rather like this notion.

Glasgow End of Life Studies Group

Are there intangible interventions that we could identify which promote and recognise the significance of aspects of human existence that have intrinsic value at the End of Life; they might be intangible in character but very very important. Issues to do, perhaps with spiritual care, opportunities to explore meanings, beliefs, values, attitude formation, the ideas that exist around notions of dignity or compassion. These would be interventions that we would put in this intangible category.

So this is our emerging taxonomy or typology of interventions and we're going to be doing more work to define these and we believe that this at the moment, and please tell us if it's not, is a comprehensive laying out of the whole range of possible End of Life interventions and we want to link that more historically to the broader emergence of the End of Life field in the global context. We think that this is one way of studying the emergence of the field to lay out this typology or taxonomy of interventions.

From that we want to and are studying some of them in more detail. There are many more interventions. I started out thinking that we could somehow catalogue these interventions and all these categories but I don't think you can – that would be some kind of encyclopedia of interventions, but we are building up a good working knowledge of many many examples of these interventions of these different types around the world.

But where we look at them in more detail we're trying to use a kind of case study method. Some of our case studies are going to be, and are, desk based, perhaps fairly straightforward to manage and implement. Some of them we see running throughout the lifetime of the project involving significant amounts of fieldwork and primary data collections. So there'll be case studies of different scales, but wherever we're engaged in that process of looking in more depth at an intervention we're trying to do it using these three dimensions: 1) at what level is the intervention conceptualised, 2) how is it being experienced by those who provide or deliver it or are somehow responsible for it 3) and how is it experienced by those to whom it's directed at the community level or the individual level. So working with that kind of framework we're beginning to pull out a number of initial case studies that we want to explore in this kind of way and I'll touch on just a few of these tonight.

These are the ones that are currently on our list, there are others as well but these are our biggest priorities. Some of them were mentioned in my initial grant application to the Wellcome Trust, others have arrived with us as we've travelled over the last 12 months of working together.

Glasgow End of Life Studies Group

I keep returning to the LCP because it preceded this session but it seems to me that it's a wonderful example of something that's not properly understood, and where the methods, the approach, the theoretical perspectives that we're wanting to explore and engage with might possibly tell us more than we have at this moment. We have at this moment many descriptions of what did or didn't work with the LCP but we don't really have much in the way of an analysis that explains it and we think that that's partly to do with the poverty of theory surrounding these descriptions of the pathway. And that's an approach that we're bringing to other case studies as well.

For example the Neighbourhood Networks in Palliative Care is something we started off with a strong interest in – it's emerging and developing into something rather broader than that, a theme around the importance of community generally in the delivery of End of Life care. But the Neighbourhood Networks have attracted a huge amount of interest. There's quite a lot of literature on them but in terms of the formal criteria that Sam was laying out earlier about evidence, about efficacy and impact and so on there is really remarkably little that's been said about Neighbourhood Networks. That therefore isn't the end of the story for us. We're interested in why this Kerala model has been so successful in promulgating itself in the South of India, but in particular what we're interested in is what happens when that model is transferred to West Bengal or to Bangladesh, or to Thailand or to Somalia. What is going on when the model is moved around in that kind of way? How is it transferred and translated in that process? So these are some of the studies that we're engaging in.

The Death Café movement is something that we're very interested in, it's kind of bubbled up even as we've been developing our work. Why is that? Why is there evidence from so many countries that Death Cafés are happening there, that there is interest in some kind of public discourse around them. To better understand that we decided to run some ourselves and I have to say that at a personal level I found them absolutely intriguing things to be involved in. But we're also asking ourselves the question 'why death cafés?' and what purpose do they serve and why have they arrived at this moment and what might they contribute to these wider debates about End of Life issues in the global context.

So these are some of the case studies that we're working on and Zaman is very keen to get out into the field and has been working already in Kerala in West Bengal and on a

Glasgow End of Life Studies Group

related project in Dhaka which is focussed on providing a Neighbourhood Network type of approach to some of the poorest people in one of the slums of Dhaka in Bangladesh.

With this study of the neighbourhood networks we come to another dimension that we're very very keen on and where it's appropriate and valuable to do so, to work with other people on specific case studies. So we discovered not long after we began, that Dr Devi Vijay, actually a management behavioural scientist at the Institute of Management in Calcutta had written a PhD on the Neighbourhood Networks and very quickly we've been able to link with Devi and Zaman (you can just see Devi in the bottom left of the picture there) has been working very closely with her. Again, an example of bringing another set of questions and theories and perspectives from the management literature into our own work in order to try and get a different kind of purchase on it.

A lovely quote here from an interview that Zaman did recently. But the Neighbourhood Networks cut across castes, they cut across class, they cut across political boundaries. They are a fascinating social phenomenon that's being transferred and translated into different contexts. We want to better understand this as a social phenomenon and not simply be confined to making an assessment of the Neighbourhood Networks in terms of their clinical efficacy or cost effectiveness.

We're very interested in the role of public health in all of this. I've been trying to trace this back a little bit in my new book and I think that the kind of notion of harnessing hospice as it then was primarily to public health thinking really gets going in the early 1980s and crucially gets going with the appointment of Dr Jan Stjernsward as the Chief of Cancer at the WHO in about 1982. The original focus is on cancer pain – how you bring a public health lens to that, which at the time seemed very counter intuitive and very very quickly WHO then started to get more involved in the terrain of defining what palliative care is and how it might be promulgated around the world. The people who were active in the pain ladder work were some of the leaders in the emerging hospice and palliative care field, notably Robert Twycross and others.

This led to the WHO's famous foundation measures being defined and from the late 1990s you see it becoming very common to make appeals to the language of public health when talking about how palliative care's goals can be promulgated. We are asking which public health is being referred to here and I've written a blog about this a little while ago having been at the Copenhagen EAPC conference where there was a lot of rhetoric about 'we need to have a public health approach to palliative care'

Glasgow End of Life Studies Group

implementation'. But of course when you start to scratch below the surface of that and particularly if you work with people who know something about the history of public health, you realise that public health is in many ways just as ill-defined, just as much a disputed space as is palliative care itself.

So I found it really interesting that palliative care, which often can be seen not knowing where its boundaries begin or end, not knowing what its definition is and it's been a huge attempt in the United States to redefine palliative care in a way that the founders of palliative care and the hospice movement would barely recognise, a disputed space around palliative care's definition and boundaries 'oh well we'll get out of this let's say, mess, by harnessing this to public health' and then you look at public health and you find that there's no public definition of it that's agreed, huge dispute about the new public health and the old public health, whether it's an epidemiological or political model etc etc. So we're really interested in this and trying to explore that in particular through the trajectory of WHO from the 1980s as the chief agent in the introduction of public health into the discourse of palliative care.

And this led us to a little study which we've just completed and in fact we've just submitted it to a journal yesterday, where we were sitting around thinking about one aspect of this public health approach and we were thinking about one of our categories of intervention, which is advocacy, and we were looking and thinking about these palliative care declarations and particularly the 2014 declaration from the World Health Assembly which came out of the global atlas of palliative care and called on all governments to engage in the delivery and integration of palliative care into their national health strategies. So we've done a piece of work and it's been particularly Hamilton that's been leading on it and he's done some diligent work digging around and searching for declarations that relate to palliative care and we're going to go on from this to look at other declarations that relate to assisted dying, End of Life issues for older people and also pain. We started with palliative care, kind of low-hanging fruit, mapping the rise and spread, content and purpose of the palliative care declarations.

This slide is already slightly out of date because after it was completed, Hamilton found a 34th one. I told Phil Larkin on the phone yesterday, the president of the EAPC, 'did you know how many palliative care declarations there are?' he said he had no idea so I said that we found 34 of them and he said 'well it makes you wonder whether we need another one', so whether there's going to be another one in Dublin in June when the

Glasgow End of Life Studies Group

EAPC meet, well you watch that space. But there is something going on. Why these declarations, what do they consist of? We see a trickle of them in the early 80s and more recently there's been a small flood of them occurring in different places and Hamilton has looked at what their purpose is, what they're setting out to achieve, what's in them, the kinds of recommendations they make, the ways that they engage in and call for action to others.

Again for us, they're data in the sense that they provide another way, another lens for making sense of the history of End of Life care globally. It's a different way of making sense of the emergence of the field to explore these declarations and their content and their geographic scope. It's very interesting that 16 of them are global, there are some very regional ones from Canada and Kerala. I didn't know, though I live in the UK that there were three declarations that related to England, explicitly linked to general elections, that were produced by the National Council. And we see the relatively small number of declarations appearing in huge countries like India and China and we noted that there were no declarations on palliative care from the United States of America. So it's telling you something about the character of the field, what's important to it and down the right hand side Hamilton's been able to identify some of the strongest themes that emerge in these declarations – issues to do with education, and policy and the provision of drugs and pain relieving medications and so on. They give you a very rich and detailed picture of what is on the mind of the palliative care world at any given point over the last few decades and how what is on the mind of those people has been translated into some kind of declaration or set of commitments or call to action.

So where are we now with our study? One year in I think we've made quite good progress. The beauty of the Wellcome Trust as a funder is they don't give you or ask you to produce in my case a 48 month Gantt chart where every month you will know exactly what you're going to have for breakfast and what you'll be doing. What they give you and I think Wellcome is very unusual in this in its humanities and ethics and society programmes is the licence to think freely, perhaps to provoke the field that you're interested in a little bit, to think outside of the box, try to draw in ideas and concepts from elsewhere and to be on a journey of discovery and exploration. I feel that's where we are with our work.

At the moment we're working on a number of concepts papers around the 'waiting room of history' around 'public health and palliative care', 'the taxonomy of interventions', the

Glasgow End of Life Studies Group

definition, we've also made a bit of traction with the case studies and the declarations one which we've now been able to finalise and write up a paper but we have other case studies around Death Cafés, self-directed interventions. The integral model of palliative care, so called, in Belgium - where you have legalised euthanasia and palliative care sitting side by side and sometimes practised integrally within the same services, often dismissed by palliative care commentators and still very poorly understood and very marginalised in the discourse. I was writing about it recently on our blog, in relation to the new EAPC paper on euthanasia. I think that could be a very very important area of study for us.

Building on our academic partnerships with colleagues in other universities around the world and in particular and I just want to close on this – promoting wider public engagement with our work. Because you saw earlier in the slide of the team that we had a public engagement person with us on the team from day one, in Catriona. When I was writing the grant application originally that post went in for Year 4 only and I began to think 'why would we do that? Wouldn't it be better, more interesting, more challenging, to build in public engagement with the work right from the start and through the process', so that's what we've tried to do. It presents all sorts of fascinating opportunities and ways to discuss and share our ideas and to engage with a variety of media in order to do that.

We have a website, well everyone has a website, we started a blog a whole year before our project started which by month 1 of the project, March last year, had already created a community of interest in work that we were doing. I think that now we've got nearly 100 posts on that blog and we have a lot of people reading it and engaging with it in various ways. We've been very active in the social media, maybe not so active as what do you call them Sam, the 'Lego Palliateurs', they seem to be very active, but we're tweeting away as well and following them a little bit.

Video, we've got a number of films, and films of lectures and talks and interviews and things on our YouTube channel. Podcasting doing the same thing. One thing that we were very pleased with that we put on the channel to mark the 10th anniversary of Dame Cicely's death was an interview I did with her just about a month before she died – an excerpt from that. Things that we're trying to add to the field, to be a resource to be a point of contact, but to get beyond the field as well. It's really heartening when you get

Glasgow End of Life Studies Group

responses to this coming from people who aren't inside the field. So that's part of the goal of the public engagement.

And also organising a number of events, I mentioned the Death Cafés, this was a Death Campfire that we had at the end of August in the beautiful region of Dumfries and Galloway where our project is located. And the death campfire took place in the context of an environmental arts festival that was 'off grid' for a whole weekend with a whole series of events taking place in a remote rural location. Trying to find different audiences, different groups, communities to engage with in different discussions about End of Life issues and interventions. These are some of the key features of the public engagement approach.

I just want to conclude with teamwork culture. I hope you don't think I'm romanticising or being cheesy here but somehow it's very important to us as a group of people to find a way of working together that respects the values of our funder in terms of open-ness and respect and commitment and to demonstrate those values in the way that our team works. So we've fostered, partly intentionally, partly unintentionally a sense of respect and kindness between our colleagues. We meet together regularly. One of the things we like to do each month instead of having a kind of staff meeting, we have something called a 'curated meeting' where one member of the team takes responsibility for the event for a couple of hours. It's usually held somewhere away from the university, so this one we call 'Coffee and Chakrabaty' - this is when Zaman introduced us to the work of Dipesh Chakrabaty some months ago in a café in Dumfries, but we've held these curated meetings in other kinds of places as well. Trying to find a way to generate a kind of culture in our team that will allow ideas and new concepts to prosper in our work.

So I'd like to conclude with where we were a year ago exactly. I was speaking at the American Hospice and Palliative Medicine Academy annual conference in Philadelphia almost exactly a year ago today about my work on the project on Death in America and I showed this short film that we'd made in advance of the start of our project and on reviewing it again one year later I think we still feel fairly confident that this film captures what our study's about and where we're trying to go.

So thank you very much for listening, we can have a bit of a discussion in the room before we all go but we will be around for the networking opportunity that exists later on and I think that will involve the ingestion of fluids and food as well. So if you want to talk to people in our team, that would be very nice, talk to our guests and please make

Glasgow End of Life Studies Group

sure you go away with the origami which you will treasure and will probably have framed on your wall before very long.

So thanks for listening and I hope you enjoy this little film - it only lasts 90 seconds.

Followed by a question and answer session which is not transcribed.