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EDITORIAL NOTE

ROBERT POWER

This special issue of the Irish Journal of Anthropology brings together a number of papers presented at the 2016 Anthropology Association of Ireland’s annual conference, Caring Cultures/Cultures of Care. The conference called for papers from Anthropology and beyond with a focus on unpacking the idea of “care” in both formal and informal settings and sought an expansive understanding of the concept. Two overlapping and interconnected accounts of “care” emerge within the following articles. First, “care” is infrastructural for human beings and appears to be a central aspect of what it means to be human. It is a subjective concept that examples an outward manifestation of human emotions and human attachment to others. Care is almost intuitively understood here to refer to “caring for” our families/communities from the cradle to the grave, so to speak, and specifically directed towards caring for people suffering from chronic illnesses. Care, thus presented, denotes intimate and inalienable human relationships where family members care for one and other.

Second, “care”, in a number of other guises presented here, informs central aspects of clinical encounters, healthcare reforms, healthcare teaching practices and healthcare policies. “Care”, sometimes combined with the terms person/patient-centered, shapes national health policies, healthcare professionals’ practices and patient engagement within formal and informal healthcare settings. Although not always explicitly expressed in the following terms, “care” policies aim to inject emotion into clinical settings. That is, “care” redefines the patient/healthcare professional’s relationship and, therefore, apparently removes barriers, imagined or real, between the patient and the healthcare professional. From this perspective, “care” informs policy and reform and, as such, seeks respect for patients, seeks co-designed decisions regarding “care” pathways and seeks to empower patients with a view towards fostering autonomous self-management. “Care”, thus presented in this second sense, denotes policy and practice and alienable human relationships where professionals care for others.

Many of the articles within this special issue problematize, scrutinize and critique the concept of “care”. Van den Buuse, for example, highlights conflicting interpretations of the concept of “care”, self-reliance and resident control amongst care-givers, family members and care-receivers in a formal care setting. Not only are “care” and notions of patient-autonomy/self-reliance understood to mean different things to care-givers and care-receivers but, even amongst care-givers in one Dutch nursing home, there is confusion about how care policies should be implemented and confusion about what “care” means in practice. Despite national policy moves towards person-centred care in Ireland, Sheehan, in suggesting that ‘care is an art form,’ in a literal rather than metaphorical sense, argues that ‘care modalities’ continue to be based on the medicalisation of chronic conditions. In other words, although health discourse conveys “care” as its central tenet, institutionalisation, pharmacological interventions and containment continue in the treatment of long-term conditions. Poelman unpacks complex discourse surrounding normal and abnormal interpretations of “care” by comparing expectant parents’ views about home birth versus healthcare professions’ views and opinions about birth in an attempt ‘to understand the perception of normality in relation to the human body.’ Thus for Poelman, “care”, as either normal or abnormal, is contingent upon contextualised/medicalised perspectives.

Staying in Ireland, O’Riordan, Kelleher and O’hAdhmaill discuss “care” from the perspective of ‘other-centeredness and relationality in people’s decisions.” These authors additionally point out
that “care” is gendered and it is frequently unpaid female family members who give care. Written into Ireland’s constitution, caring is “women’s work”, notes Hanlon, and women’s responsibility for caring advantages men within the labour market, politics and other areas. Thus, as Hanlon suggests, the historically contextual gendering of care in Ireland reinforces the “cultural marginalisation of men from caring.” In Spain, Bofill Poch notes the rise in female migrant care-givers where, as a result of both weak labour protection and the economic crisis, domestic workers’ rights are being diminished, instances of abuse meted out against domestic workers are rising and the work of migrant care-givers in maintaining and reproducing society is not valued. Still in Spain, Comas D’Argemir Cendra notes how the fallout from the economic crises is redrawing gender lines in the home as the number of men working as unpaid carers is increasing. That is, the precarious nature of employment in Spain means it is more difficult for men than women to secure permanent employment. Rational, logical and economic choices, often viewed as the binary opposite of a subjective emotional human behaviour such as “care”, have encouraged men to stay at home and care whilst women earn the principal family incomes. And, involving men in caring for adults, ‘whether in response to circumstantial needs, or as new agents participating in family and community work’ (Comas D’Argemir Cendra) is a considerable challenge. Care-givers, in this sense, are not fully valued by society. And “care” is located in an ideological sphere where those few who are financially rewarded for caring—without whom society could not be reproduced—are mistreated, exploited and undervalued.

Walther compounds the gendering of “care” as she unpacks ideologies and top down process that teach, through professional schools, female Slovakian care workers bound for Austria to become the “ideal” Westernised care workers. Viewed as “products” shaped into suitable commodities for a Western market, Slovakian care workers, Walther argues, ‘strive to meet customers’ demands,’ suppress complaints about working conditions and, as it were, domesticate themselves to suit the requirements of the Austrian market. In contrast and blurring the lines between formal/informal and professional/family care-givers Hedegaard Ludvigsen, draws from kinship studies and highlights the manner in which care-giving realises familial relationships between professional healthcare workers and care-receivers. As a result of historical notions regarding an almost parental-like relationship between of the Danish state and its people, Hedegaard Ludvigsen argues that relatedness and new kinship bonds emerge as a result of sharing substances in the home. If caring realises emotional bonds, it may additionally “strike back”, as Reinsch argues. That is to say, skipping therapy and rejecting care “seemed a rational choice” when young adults suffering with a chronic condition wanted to avoid the stigma of being seen as “ill” and wanted to keep their condition “invisible to the public.”

Highlighting further ambiguities inherent with concepts such as patient-centered care and/or patient choice, Sciolli suggests ‘how it is necessary to disentangle the idea of good care from its immediate association with patient choice.’ That is, care for anorexia patients means ‘being able to enact [by force] the practical requirements of care even when patients...would refuse them’ and, therefore, choice, self-management and co-decision making are condition specific issues that, once viewed from the perspective of a specific condition, negate generalised policies relating to patient choice. Lolich and Lynch however, note the emergence of a paradox between the medical expect and patient choice as a result of an ‘increased professionalization of death, and notions of a culturally constituted ‘good death’ and a ‘shameful death.’ Similar to Poelman’s discussion regarding “normal” and “abnormal” notions of birth, death suffers a similar faith for Lolich and
Lynch where a ‘good death’ means choosing a medicalised notion of death and patient’s who refuse to accept their terminal condition are labelled pathological.

Ní Mhórdha offers a different perspective on “care” and a critique of culturally constituted and gendered ideologies of “care” when discussing female genital cutting (FGC) ‘as a violation of the right to bodily integrity.’ For Ní Mhórdha, African FGC practices are perceived of as a homogenous ‘cultural’ practice that are symbolic of patriarchal oppression, yet Western ‘male genital cutting (MGC) procedures that remove the foreskin of non-consenting babies or children...are not considered similarly oppressive or in violation of human rights.

The contribution by Kuckert-Wöstheinrich, Esterhuizen, Maz, Gilmartin and Chin, collates five papers presented at the AAI conference that critically examine how “care” and caring is presented in nursing literature. Contextualised against a backdrop of recent reports regarding the need for “care” to be patient-centred, compassionate and well informed, this contribution examines “care” through ‘philosophical and empirical approaches and discuss[s] it in terms of clinical, organisational, and educational perspectives.’ Kuckert-Wöstheinrich et al, note how caring within nursing is ‘multifaceted and complex from both personal and organisational perspectives’ and emphasise how the literature fails to ‘define caring in any practical or applicable way’.

As “care” appears to be central to what it means to be human and being human is subjective, historically contingent, culturally contingent, more than the sum of all of its parts and a kind of jumble of things, piled up piecemeal overtime, a summary of the articles in this special issue reveals ambiguities, confusion and context/condition dependent interpretations of “care”. “Care” and caring is, thus, heterogeneous—much like the people who practice “care” either formally or informally in our homes or formally or informally in clinical setting. I would like to thank the contributors to this special issue for answering a call from Anthropology and beyond to unpack the idea of care in both formal and informal settings and articulating an expansive understanding of the concept. Their contributions raise questions, blur lines, critique concepts and initiate to beginnings of an interdisciplinary conversation.
GENERAL EDITOR’S INTRODUCTION

James Cuffe

This issue of the Irish Journal of Anthropology follows (belatedly) from the Anthropological Association of Ireland’s conference in 2016. This collection of papers showcase the importance of anthropological engagement in medicine. The conference was proud to have Arthur Kleinman as keynote and we include an interview held with him on the sidelines of the conference in this issue’s interview section.

Our regular “Comment On” section follows the theme of the conference, and this issue, and invites us to participate in an upcoming conference in Frankfurt being held by our friends and colleagues at the Social Pathologies of Contemporary Civilisation; more information can be found at www.socialpathologies.com.

The journal is as always an endeavour by a small number of hard working individuals, I thank Robbie for devoting his time and patience in seeing this issue through. I am delighted to introduce new members of the team, our new Managing Editor Máire Ní Mhórdha and Digital Editor Lobna Abulhassan will provide focus and direction on specific concerns at a time when the journal is growing and facing challenges as a result. I also say a sincere thank you to Ioannis and Kathleen who have both been stalwarts for the journal over the past years. They have given more of their time to the journal than the AAI can know so on behalf of all of us I wish them the very best in their future endeavours. Jill O’Mahony joins us our new Book Review Editor while Sitara moves to take on Ioannis’ duties managing the Comment On section.

The journal is on the cusp of being financially independent which will be a boon for both the IJA and the AAI. I look forward to the changes the journal will necessarily undergo with both Máire’s and Lobna’s initiatives for the print and digital editions and I urge everyone to support them going forward with both time and resources as necessary. As always I invite submissions for general issues and also any comments or ideas from our readership. We seek to improve the journal despite the constraints we operate under.

Thanks to the IJA team and wider IJA community who spare their time and energy for the journal in service of the anthropological community of Ireland.
Susanne van de Buuse is a PhD Candidate at the Department of Anthropology of the University of Amsterdam. Her research focuses on the practical implications of the new ideology of the Dutch state in the care and welfare domain, which makes larger appeal on the self-reliance (“zelfredzaamheid”) of elderly people and urges them to stay in control (“eigen regie”) of their life. In Dutch nursing homes care workers are encouraged to put more effort into promoting residents’ self-reliance and control as well and also to increase the involvement of family members. My ethnographic research looks at how these interpretations of the autonomy ideology play out in the daily care activities between care workers and residents and focuses on the complexities care workers experience as self-reliance and client control change their professionalism.

Cormac Sheehan

Cormac Sheehan is a research officer at the Department of General Practice in UCC and is based in Mallow Primary Healthcare Centre. He is currently researching on themes concerning dementia, dementia care and experiences of cognitive assessments.

Sanna Poelman

Sanna Poelman received her bachelor’s degree in Cultural Anthropology and Development Sociology from the University of Amsterdam, the Netherlands, where she focused on topics as identity-formation, power structures, and violence. During her master's degree in Social Anthropology (CREOLE) at Stockholm University, Sweden, she spent one semester in Maynooth, Ireland as an exchange student and got excited about writing her thesis on childbirth in Ireland. Her current anthropological interests lies in the relation between biomedical advancements, risk, and the 'normal' body. She hopes to can start doing research in this field as a PhD student in the coming up year(s).

Sorcha Ní Chruílaoich & Gearóid Ó Cruílaoich

Professor Ó Cruílaoich is an graduate of University College Cork and earned his graduate degree in Folklore at the University of Pennsylvania. He has worked as a Fulbright grant recipient and as an Associate Professor of Folklore and Ethnology at University College Cork. His most recent publication is The Book of the Cailleach, an analysis of the “wise woman” in the Irish oral tradition. Professor Ó Cruílaoich, who established the Ethnology Department at the National University Cork, is regarded as the eminent senior folklorist in Ireland. In his long career, he been a visiting professor at Cornell, UCLA and Boston College.

Dolors Comas d’Argemir

Professor of social anthropology at the Universidad Rovira y Virgili (Tarragona, Spain). She was a member of the Catalan Parliament and of the Catalan Audiovisual Council between 1999 and 2012. Her research has included work on changes in the family, women and work, public welfare policies, economic anthropology and political ecology. Some of her most notable publications are Vides de dona (1990), Estudios de antropología social en el Pirineo aragonés (1994), Trabajo, género y cultura. La construcción de desigualdades entre hombres y mujeres (1995), Antropología económica

**EVA-MARIA WALTHER**

Eva-Maria studied *Empirische Kulturwissenschaft* (Historical and Cultural Anthropology) and *Slavistik* (Slavic languages and culture) for her BA at Eberhard Karls Universität Tübingen, Germany and the University of Pécs, Hungary. She holds a Masters in Social Anthropology from the University of Stockholm and is currently one of the editors of the anthropological podcast AnthroTalking. Among her fields of interest are processes of social and political transformation in post-socialist societies, as well as discourses on nationality and belonging. She is currently preparing her doctoral thesis on notions of tolerance in civil and church affiliated organizations in Slovakia.

**BODIL HEDEGAARD LUDVIGSEN**

Research Assistant, PHD, Department of Anthropology, Center for Healthy Ageing, Department of Anthropology, University of Copenhagen. Research interests: Old people living alone in their home, social relations, aloneness, citizenship, home nursing.

**STEFAN REINSCH**

Stefan Reinsch is a medical doctor and anthropologist working at the Department of Pediatric Pneumology and Immunology, Charité – University Medical Centre, Berlin, Germany. In 2013–15 he was postdoctoral researcher at CERMES3, Paris, where he investigated the entanglements of clinical and scientific work in the negotiations around the diagnosis ‘at-risk mental state’ in French- and German-speaking psychiatry. This paper draws on his PhD research about the strategies young people with cystic fibrosis use as they integrate their therapy into daily life.

**GIULIA SCIOLLI**

Giulia Sciolli graduated in 2013 in Anthropology and Development Studies at the University of Sussex (Brighton, UK), after receiving a bursary to attend the University of British Columbia (Canada) for a semester in 2012. In 2014 she obtained a Master of Science in Medical Anthropology at University College London (UK), with the Dissertation: “*The Soul Needs a Place*: Envisioning a New Treatment for Eating Disorders. From September 2014 to September 2015 she attended a specialization course on ‘Good treatment practices for Eating Disorders’ offered by the University of Perugia (Italy). From June 2015 to May 2016 she has collaborated with the ‘Laboratorio Management e Sanità’ of the Scuola Superiore Sant’Anna in Pisa (Italy) with a research bursary. Here she did qualitative research in the health sector analysing both patients’ and healthcare professionals’ behaviour, with a focus on the variability in the results of care. Her main topics of interest include: the anthropology of medicine and of healthcare systems; the anthropology of psychiatry, mental illness and mental health; the anthropology of Eating Disorders and their treatment.
**Luciana Lolich**

Luciana Lolich has worked in higher education for the past twelve years, teaching at undergraduate and postgraduate level. She holds a PhD in Equality studies from University College Dublin. Her thesis examined consumer choice in higher education. She is interested in deconstructing consumer choice in areas like education and health. Luciana is currently a post-doctoral research fellow at University College Dublin, researching choice in palliative care. Her work has been published in books and peer-reviewed journals.

**Kathleen Lynch**

Kathleen Lynch is the UCD Professor of Equality Studies and an Irish Research Council Advanced Research Scholar for 2014-2017. An academic and an activist, she is guided by the belief that the purpose of scholarship and research is not just to understand the world but to change it for the good of all humanity. She has published and campaigned on equality issues, both nationally and internationally. Her most recent co-authored books include *Affective Equality: Love, Care and Injustice* (2009), and *New Managerialism in Education: Commercialisation, Carelessness and Gender* (2015).

**Máire Ní Mhórdha**

Máire Ní Mhórdha holds a PhD in social anthropology from the University of St Andrews. Her research interests include the anthropology of development, gender, human rights, and elites. Her doctoral thesis was a critical ethnography of an American human rights NGO in West Africa.

**Arthur Kleinman**

Kleinman is professor of medical anthropology in the Department of Global Health and Social Medicine and professor of psychiatry at Harvard Medical School. He is the Esther and Sidney Rabb professor of anthropology in the Department of Anthropology in the Faculty of Arts and Sciences (FAS), and was appointed the Victor and William Fung director of Harvard University’s Asia Center from 2008–2016. In 2011, Arthur Kleinman was appointed as a Harvard College Professor and received the 2011 Harvard Foundation Distinguished Faculty Award. He chaired the then Department of Social Medicine at HMS from 1990 until 2000, where from 1993-2001 he was the Presley Professor of social medicine, and chaired the Department of Anthropology at Harvard’s Faculty of Arts and Sciences from 2004 to 2007.
The current era may be characterised by various forms of suffering and resilience with contemporary malaises, diseases, illnesses and syndromes manifesting in relation to cultural pathologies of the social body. Usually these conditions – depression, anxiety, suicide & self-harm, disorders of consumption, stress related illness, to name just a few – are interpreted clinically in terms of individualized symptoms and framed in demographic and epidemiological profiles. They are represented and responded to discretely, as though for the most part unrelated to each other; each having their own professional discourses of etiology, diagnostics, therapeutics, as well as their task forces developing health strategy and policy recommendations and interventions. However, these diseases also have a social and cultural profile, one that transcends the particularity of their symptomology and their discrete etiologies. These pathologies are diseases related to disorders of the collective of contemporary society.

A multi-disciplinary approach is needed to address questions of how these conditions manifest at the level of individual bodies and minds, as well as how the 'bodies politic' are related to the hegemony of reductive biomedical and psychologistic perspectives. Rejecting such a reductive diagnosis of contemporary problems of health and well-being, the central research thesis that should serve as a guide is that contemporary epidemics are to be analysed in the light of individual and collective experiences of profound and drastic social changes and cultural shifts. More specifically – but not exclusively – a focus on the social dynamics of suffering. In times where society is neglected & disparaged and individual psychological resilience is advocated & promoted as substitute and panacea we want to focus on understanding how social and cultural conditions moderate the experience of suffering, whether collective suffering as a result of war, natural catastrophes or economic crises, or individual suffering, insofar as it has primarily societal causes. For our upcoming 2017 conference to be held in Frankfurt we invite scholars to address such questions as:

- Is the focus on resilience adequate to the moral-political questions raised by Europe's so called migration & refugee crisis?
- Could the concept of resonance offer a better understanding of suffering?
- Due to the transformation of work and the psychosocial costs associated with these changes, as well as the increasing tendencies towards social exclusion and
social inequality (including inequities linked to gender), social suffering has become a characteristic & general experience of industrialized nations as well. The notion of social suffering highlights the fact that the suffering in question is caused by structural conditions and remains embedded in them.

- Psychologization of suffering. Is the notion of “social pathologies” as well as the ongoing question of the diagnostic potential of the social sciences already part of a neglect of society itself and playing into the hands of psychology? What is the role of therapy culture in this development?

- Common to all contributions to the field of social pathologies is both the interpretation of social suffering as an increasing effect of neoliberal capitalist socialization and its determination as a theoretical reference point for social critique. Whilst attending to the particular ways in which individuals struggle to make ‘the problem of suffering’ productive for thought and action, it also works to understand how, through to the level of collective experience, this contributes to wider dynamics of social change. Is, again, the concept of resonance an adequate starting point?
ARTICLE

CONFLICTING INTERPRETATIONS OF THE CONCEPTS ‘SELF-RELIANCE’ AND ‘RESIDENT CONTROL’ AFTER THEIR INTRODUCTION IN A DUTCH NURSING HOME

BY SUSANNE VAN DEN BUUSE

Abstract: According to the Dutch government elderly people should be self-reliant as long as possible, because this will prolong their well-being and will reduce care costs. It is assumed that to be self-reliant elderly people need to have the control over their life and support as long as possible. This paper focuses on the ways in which care workers on the somatic ward of a Dutch nursing home applied these two concepts in their work. The paper demonstrates that sometimes care workers interpreted the concepts differently than residents and their family members, which caused conflict between both sides.

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Introduction

Recently in the Netherlands drastic liberal reforms to the health care system were made, ultimately aimed at making people more responsible for arranging their care and support by using their own means instead of relying on state provision. Based on the assumption that people are capable of more than they appeared to be a ‘participation society’ was envisioned, with citizens who are ‘zelfredzaam’, or self-reliant, if necessary through help of their social network, and have ‘eigen regie’, or ‘control’ 1. The Dutch government assumes that increasing people’s self-reliance will result in a reduction of care costs deemed necessary and increase people’s well-being and dignity. On elderly people therefore an appeal is increasingly being made to take care of themselves more and live at home for longer, assisted by their family if necessary. In Dutch nursing homes the concepts of self-reliance and control are applied as well, which is the focus of this paper. The paper is based on the results of an ethnographic case study which explored how care workers of a somatic ward applied these concepts to their daily care practice and the complexities this resulted in. The paper demonstrates that in some situations care workers used a different interpretation of control than residents and their family members, which caused conflict between both sides. In these situations residents and family members interpreted resident control as care workers listening to the resident’s wishes, while care workers interpreted resident control as being self-reliant, and
thus, paradoxically, they did not acknowledge residents’ wishes for assistance if they assumed them to be self-reliant.

As discussed above, self-reliance and control form the key concepts of the Dutch government’s new ideology, yet the way the government and authoritative organizations in elderly care such as Actiz\textsuperscript{2} and Vilans\textsuperscript{3} use the concepts is ambiguous. Vilans (2013) provides a clear definition of self-reliance as ‘the capacity of people to rely on themselves in all domains of life with the least amount of support and care as possible. This concerns social, physical and cognitive skills (...’). Vilans defines control as ‘being in control over one’s life and support’. Control then resembles the concept of autonomy, which is used sometimes as well. Vilans, Actiz and the government link the concepts in several ways which are slightly different, but overall it is assumed that being self-reliant is the most important and that this requires being in control (Actiz, 2014).

Methods
This paper is based on an ethnographic study which was conducted in Alethea (pseudonym), a medium-sized care organization in the Netherlands which provides care for mainly elderly with mild to severe somatic and psycho-geriatric disorders. This paper only concerns that part of the study conducted on a somatic ward, where residents lived who suffered from somatic illnesses with no clear indications of a dementia diagnosis. From May 2014, when the management started a ‘culture change’ program for care workers to teach them how to increase the residents’ self-reliance and control, to the end of the program in September 2015 I conducted participant observation, in which I followed the daily work life of a care team of a somatic ward and a care team of a psycho-geriatric ward. I also included the management by attending meetings and conducting interviews and I studied relevant organizational documents. I focused on the different ways care workers applied self-reliance and control in their daily care practice and how they used the concepts to justify their actions. Regarding the latter I am inspired by the work of Boltanski and Thévenot on how ‘ordinary people’ justify their actions (1991). In line with Jeanette Pols’ work (2000) I focused on performances by observing actions of the care workers and discussing these with them.

Self-reliance and control according to the management

Adhering to the government’s assumptions, the management of Alethea wanted to increase residents’ self-reliance and control. Their interpretation of self-reliance mainly concerned performing ADL care activities independently as much as possible, so they assigned care workers with the task to encourage residents to do more ADL care activities\textsuperscript{4} on their own. This reflects a notion common in care, which is striving for residents to do as much on their own as possible without help (Pols, 2000). The management further argued that the care workers had made residents passive because they always assisted them even though they were able to manage by themselves. This meant that residents, even the severely ill ones, were assumed to be capable of more than they appeared to be and that they needed to be encouraged to perform more care activities themselves. In line with the government it was assumed that this would benefit them and save the care workers time.

Resident control was interpreted by the management as asking for and listening to residents’ wishes and trying to realize these within one’s power. Resident control too had
to be applied mainly in the ADL context in their interpretation, but also in a broader sense to life activities. If a resident used to swim once a week for example when he still lived at home, then the care workers should ask him if he would still like to do this and if yes, they should try to find a way to realize this. As with self-reliance, the management argued that the care workers had always decided on the residents’ behalf and by doing so made them passive. They therefore urged care workers to ‘give the control back to the residents’ and adapt their practices to the residents’ wishes ‘instead of the other way around’. This meant they had to stop their current practices of standardization and set daily structure and had start to customize.

The care workers were not provided with more detailed instructions, as the management believed in working ‘bottom-up’ and letting the care workers find out how to apply the two concepts themselves. The management did acknowledge that self-reliance and control could be at odds when residents refused to be more self-reliant. Yet, like the government, they considered self-reliance as more important than resident control, which meant that care workers should continue to encourage these residents.

In the following section two interpretations of resident control as used by the care workers are discussed. In the section following after is demonstrated how in some situations the care workers’ interpretation of control conflicted with residents’ and their family members’ interpretation of control and how this caused frustration on both sides and conflict.

The first interpretation of resident control is displayed in the fragment below, in which three care workers discuss the meaning of self-reliance and control together.

SB: ‘Ok, so what does it entail?’
Chrissy: ‘Resident control? Well that is letting [residents] do [their] own thing, having a say in things’.
Francesca: ‘Development of Resident Control’, people who live here, they need to do as much as they can by themselves. They have to take control of their life as much as possible and of their own decisions, what happens during a day (…). ‘That has to be developed because a lot of people had lost that of course and are rather hospitalised in a nursing home like this.’

In this fragment the care workers describe resident control as having a say in things and in [making] their own decisions, what happens during a day. This means ADL situations, such as letting residents decide at what time to get out of bed, which they would explain in the continuation of their discussion. This interpretation of resident control is the one propagated by the management. I refer to this as the ‘narrow’ interpretation of resident control. Francesca also describes resident control in another way by saying that residents need to do as much as they can by themselves. In this interpretation then, self-reliance is necessary in order to be in control over one’s life. This interpretation is represented more clearly in the fragment below, in which Georgette explains to me how they enabled residents to eat without assistance by providing them with adapted cutlery and plates.

Georgette: ‘So before we say “we will do everything” then they can first try it themselves and often that just works really well and then they still have the control in their hands [when they realize] like “oh, I can do this myself”.’
Georgette interprets resident control not in the ‘narrow’ sense of deciding what happens during a day. Rather she seems to refer to a more overall state of being in control over one’s life which she feels will be the result of being able to eat without assistance again and thus, of being self-reliant. I refer to this interpretation as the ‘broad’ sense of resident control. The strong relation between self-reliance and resident control in this interpretation is illustrated beautifully by Georgette’s phrase having the control in their hands. In this interpretation the resident is not in control in the ‘narrow’ sense, because when he would wish to be assisted in eating while he is capable of eating independently through using the cutlery, his wish would not be acknowledged in order to enlarge his self-reliance and thus his ‘broad’ control over his life. This is also what the management instructed the care workers to do because they believed residents have been made passive, a belief which corresponds to the care workers’ notion of residents being ‘hospitalised’, as Francesca’s words show. Thus, it is assumed they need to be encouraged to be self-reliant. Somewhat paradoxically then, what resident in control means for a resident is decided by the care workers instead of the resident.

In sum, resident control is interpreted by the care workers in two ways, the ‘narrow’ sense of asking for and listening to residents’ wishes, and the ‘broad’ sense, in which resident control refers to a more overall state of being in control over one’s life which requires self-reliance. Interpreting resident control in a ‘broad’ sense paradoxically means denying resident control (the ‘narrow’ sense) and not acknowledging a resident’s request for assistance while he is capable himself, because self-reliance is assumed to be necessary to be in control in the ‘broad’ sense. This interpretation corresponds to the management’s instruction to encourage self-reliance even when a resident is capable but refuses as this likely is a sign of passiveness, or in the words of the care workers, of ‘hospitalisation’.

Conflicting interpretations of resident control between care workers and residents and family members

The belief that self-reliance is necessary to increase residents’ control over their life provided care workers with a justification to encourage residents to perform activities themselves if they considered them capable of this. Their belief that residents were ‘hospitalised’ and the management’s belief that increased self-reliance of residents would save the care workers time, provided complementary justifications. When care workers interpreted resident control in the ‘broad’ sense and encouraged residents to be more self-reliant to enlarge their control, residents and/or their family members sometimes interpreted control in the ‘narrow’ sense and claimed that care workers had to listen to their wishes. Often conflict between care workers and residents and/or their family members was the result.

Encouraged by the care workers, some residents started to perform more activities themselves. Other residents refuse to do this or claim they are incapable of performing the activities the care workers encourage them to perform. An example of the latter is Mrs. Langley.

Mrs. Langley: ‘They want me to wash myself and dress myself on the upper side [of my body], and then I say: “I can’t, because I’m too tired”, and then they say: “Come on Mrs. Langley, you can do it! Try it and when you are unable to, just call us”.’
The nurses use the ‘broad’ interpretation of resident control and try to make Mrs. Langley more self-reliant, which causes Mrs. Langley to feel upset because she feels incapable of washing the upper side of her body and her request for assistance is not acknowledged by the care workers. Her words reflect the ‘narrow’ interpretation of resident control.

In some cases residents’ family members too interpret resident control in a ‘narrow’ sense and claim their relative is incapable of doing what the care workers ask them to do, as in the case of Mrs. Wright.

Mrs. Wright moved to the nursing home three months ago and has Parkinson’s disease. The care workers often leave it up to Mrs. Wright to take initiative as they feel she is still capable of this and always tell Mrs. Wright ‘if you need something, you let us know. The nurses also encourage Mrs. Wright to take initiative in creating her own social network, something which Mrs. Wright is longing for as she often feels alone. In both cases however, Mrs. Wright does not take initiative most of the time. Her daughter Mary feels they are overestimating her: ‘They still expect her to do a lot on her own, while she [can’t]. Because she has her good moments and then she comes across very clear-headed.’ Coordinating nurse Leah tells me: ‘[Mrs. Wright and her daughter] expect us to encourage her, but on this ward we have resident control, people have to indicate what they want themselves.’

Using the ‘broad’ interpretation of resident control Leah and her colleagues leave it up to Mrs. Wright to take initiative when she needs something from them and when she wants to create a social network for herself. They do not acknowledge Mary’s wishes to assist her mother. This upsets her as she claims her mother is incapable of what they ask her to do and wants them to assist her more (the ‘narrow’ interpretation of control). Their conflicting interpretations resulted in a troubled relationship.

A similar example is the case of Mrs. Hathaway. She seldom wishes for assistance and she shows she is still capable of performing ADL activities and making her own decisions, and so the care workers encourage her in this. Daughter Annabel however feels that although she seems capable, she is not, and so she feels, reflecting the ‘narrow’ interpretation of resident control, that the care workers should listen to her decisions instead. The care workers perceive her as ‘difficult’, as they feel she is imposing her wishes on her mother and diminishing her self-reliance. When discussing with her colleagues how to deal with her behavior, Lianne, using the ‘broad’ interpretation of resident control, suggests to say the following to daughter Annabel to keep her from interfering:

Lianne: ‘Perhaps you can say: “Well madam, we are here for your mother, and your mother decides what she wants. (...) We are very into resident control here, so if your mother indicates she doesn’t like us to stand next to her when she is sitting on the potty chair, then we are not going to stand there.” It is not as if we have to listen to the family, mind you!’

Lianne’s words clearly show the ‘broad’ interpretation of resident control as she feels Mrs. Hathaway’s self-reliance should be encouraged to let her be in control over her life. This collides with Mrs. Hathaway’s daughter Annabel’s ‘narrow’ interpretation who feels she should decide for her mother. Again, a troubled relationship was the result of these conflicting interpretations.
In sum, care workers’ interpretation of resident control in the ‘broad’ sense, entailing encouraging residents to be more self-reliant, often collides with residents’ and/or their family members’ interpretation of resident control in the ‘narrow’ sense which entails listening to their wishes. This difference often led to situations of frustration on both sides and conflict. The paradox inherent in the ‘broad’ interpretation of resident control seems to play a key role, which is that the ‘broad’ interpretation of resident control as requiring self-reliance means that care workers decide for residents how they can be in control over their life, instead of residents themselves or their family members in case they feel their relative is incapable of deciding.

Conclusion

‘Zelfredzaamheid’ (self-reliance) and ‘eigen regie’ (being in control) are the key concepts in the new health care policies instigated by the Dutch government. The government claims that elderly people should be self-reliant as long as possible because this will prolong their well-being and will also reduce care costs. It is assumed that to be self-reliant elderly people need to have the control over their life and support as long as possible. Both concepts are also applied in nursing homes. This paper focused on the different ways in which care workers applied the concepts in their daily care practice and how they used the concepts to justify their actions. This methodological lens is based on the work of Boltanski and Thévenot (1991) and Jeanette Pols (2000).

The paper demonstrates that care workers used a different interpretation of control than residents and their family members, which created conflict. Whereas residents and their family members interpreted resident control in a ‘narrow’ sense as listening to the resident’s wishes, care workers had a different interpretation of resident control in a ‘broad’ sense. In this interpretation resident control required self-reliance, which meant the care workers did not acknowledge residents’ wishes for assistance when they estimated residents capable enough to perform the particular activity themselves. This interpretation matches the government’s interpretation, who assumes that being self-reliant is the most important and that this requires being in control (Actiz, 2014), which is used in a ‘narrow’ sense. This ‘broad’ interpretation paradoxically means that what resident in control means for a resident is decided by the care workers instead of the resident himself. These different interpretations caused frustration on both sides and conflict and sometimes resulted in a troubled relationship between care workers and residents and their family members.

The welfare state model which prevailed in most western European countries in the past decades resulted in the public perception of care homes and nursing homes as places where one is cared for and is able to live a quiet life relieved from duties and obligations, which are taken up by the care workers. The strong focus on self-reliance resulting from the new ideology upheld by the government is therefore not what residents and their family members expect to find in a Dutch nursing home and therefore they often resist to the care workers’ attempts to make residents more self-reliant. Care workers often label this behaviour as ‘hospitalisation’ (learned passiveness), and thus continue to encourage residents to be more self-reliant. However, there is also a risk of overestimation of residents’ capabilities. Regarding the increasing work pressure for care workers resulting from the continuous cut backs it is attractive for them to think that residents are capable of being more self-reliant, as it is assumed this saves time.
References


Notes

1 The Dutch word ‘regie’ is mostly used in the context of film making and refers to the activities of the director, called ‘regisseur’ in Dutch. He has the ‘regie’, which means he is in control of the filming process. For legibility purposes ‘eigen regie’ will be translated as ‘resident control’ when referred to in a nursing home context. In literal quotes from care workers the Dutch term ‘eigen regie’ is used to show the way they used it in Dutch.

2 Actiz is the Dutch association for residential and home care organizations and infant and child health clinics. Actiz promotes the interests of its members in such a way that the perspectives and needs of its members are heard and addressed in national health policy development, legislative and regulatory debates, and judicial matters. Actiz also assists in establishing a comprehensive continuum of care, and in the development of appropriate quality of life standards for care for the elderly (Over Actiz, Actiz website).

3 Vilans is the national center of expertise for long-term care Vilans operates at the interface between policy, science and real world practice. Vilans is partly financed by the state (Vilans website, 22-6-2016).

4 ADL stands for Activities of Daily Living, which include washing and bathing, getting dressed, grooming, using the bathroom, walking, eating, drinking and taking medicine.

5 ‘Development of resident control’ (‘Ontwikkeling Eigen Regie’ or in short, ‘OER’) is a model that entails both self-reliance and resident control. As their team manager had introduced the ‘OER’ model a little more than a year ago, the care workers of the somatic ward were already familiar with the two concepts.
ARTICLE

PRESSURE PLAY: REFLECTIONS ON FORUM THEATRE AND THE ART OF CARING FOR PEOPLE WITH DEMENTIA

BY CORMAC SHEEHAN, CHRIZINE BLACKHORSE, DAVID RAMSEYER, AMY MURPHY & VICTORIA HOWSON

Abstract: Central to the social psychology and biomedical modalities of care for a person living with dementia is the issue of subjectivity. Despite clear moves to Person-Centred Care (PCC), care modalities for persons with dementia are still based widely on the medicalisation of dementia. At the sharp end of these medical modalities are institutionalisation and pharmacological interventions and containment. This paper examines briefly different care modalities to provide context. The focus of the paper is on the development of a forum theatre project for carers of those with dementia. The paper concludes that the validation by carers of the realities of a person with dementia is a mirroring of the somatic and cognitive changes. The paper suggests that care is an art form.

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Introduction

Dementia is an umbrella term for a wide variety of conditions associated with a degeneration of cognitive and physical capacity. Although the term ‘dementia’ is now used widely in Ireland, it is stigmatised in other European countries, in particular the Franco-speaking countries where dementia – or the root word de-mente – means ‘to be out of one’s mind’ and is used to describe madness. In France, ‘senility’ is still used, and ‘Alzheimer’s’ is used also. For the purposes of this paper, the term ‘dementia’ incorporates the specific symptoms associated with conditions such as Alzheimer’s disease and the resulting symptoms that occur, for example, after a stroke. The mental image conjured up when a person says the word ‘dementia’ or ‘Alzheimer’s’ tends to be that of an old person losing their memory and capacities. However, with greater interest in dementia, early onset of dementia has become very much regarded as a reality. Diagnosis is also different across Europe with, for example, the time of the appearance of symptoms and diagnosis ranging from ten months in Germany to thirty-five months in the UK (Innes: 2009). Although there has been no scientific breakthrough in the treatment of dementia over the last thirty years, the field of dementia can no longer be considered in ‘infancy’ as
‘attention to diagnostic description and classification, treatment, and management alternatives have generated a scientific base from which clinicians and researchers can proceed to generate evidence for efficacy and effect treatment for the behaviours associated with dementia’ (Bourgeois and Hickey 2009: 6).

The support for persons with dementia through health and associated professionals centres on identification, assessment, intervention, counselling, collaboration, case management, education, advocacy and research (Bourgeois and Hickey, 2009). The aim of any work with a person with dementia and their carers is to help achieve the best quality of life. The work presented here falls generally under the banner of education, advocacy and intervention.

**Discourse of Loss and Medicalisation**

The medicalisation of dementia is – according to Beard et al. (2009) – woven into a discourse of loss. The language and rhetoric used to describe dementia is loss-driven. Loss is not restricted to capacities, somatisation or cognition, but rather the primary loss is of the self. Cohen and Eis dorfer (1986) and Fontana and Smith (1989) use terms like ‘dissolution’ and ‘unbecoming of the self’. Aronson and Lipkowitz (1981) describe dementia as an extinction of personhood, and Kastenbaum (1987) argued that dementia caused a death-in-life or living death. Whether these opinions are true or not does not matter; it is society that will ascribe or graft the social being onto the corporal body. Society gives meaning to illness and to how we as people respond to persons with that illness. In the case of dementia, a social death has been postulated as being evident. In their study of the existence of the social death, Sweeting and Gilhooly (1997) argue that the three groups most associated with social death – people with a lengthy fatal illness, the very old and those inflicted with loss of personhood – ‘coalesce in the case of dementia’. In the case of dementia, it may not be enough for a person to retain habits, traits or memories. Society, according to Sweeting and Gilhooly, ‘may view or treat the dementia sufferer as a liminal or non-person, who is demonstrably making the transition from life to death’ (1997). The act of transition and liminality of the person with dementia would suggest the presence of a social death. The echoes of Van Gennep’s work and the thresholds of participation, liminality and rites of passage are evident. However, Sweeting and Gilhooly argue that a social death is determined largely by social distance. Those close or within what Mary Douglas would call an inner circle do not regard people with dementia who they know as being socially dead. For Sweeting and Gilhooly, carers – especially relatives and friends – do not allow the person to become socially dead for a number of reasons – namely, the person is physically present, there is hope of a connection to the person and it would impact the quality of care. Sweeting and Gilhooly found that people caring for those with dementia did not allow their physical appearance – the hair, clothes and cleanliness of the person with dementia – to become unkempt. This care for the body is the embodiment of social conformity and the antithesis of social death. According to Pearlin et al., ‘… giving care to a person is an extension of caring about that person’ (1990:583). Although there have been significant changes in how dementia is perceived, the universality of PCC is not evident. Lynam (1989) argued that the medicalisation of dementia is an example of the ‘medicalisation of deviance’, whereby behaviours associated with dementia are ‘explained by pathological conditions of somatic origin subject to medical authority’ (1998:598). More recently, Locke, in discussing the difficulties in diagnosing and treating Alzheimer’s, stated that ‘Alzheimer’s is an elusive mobile target in which the brain and mind are not necessarily in sync’ (2013:3).
The difficulty of diagnoses and the trial and error approach in efforts to find stable treatments and cures for dementia, combined with an almost universal over-dependence on family, relatives and friends to provide care, have created an intersection for competing discourses and modalities. It would be remiss to dismiss the intrinsic value and achievements the medical model has attained or, as Harding and Palfrey (1997) put it, ‘society needs dementia to be medicalised as, if it is classified as a disease, it holds out the prospect of a cure for ageing and for death’. The contribution of social science to dementia studies is direct, as discussed below, but also indirect, as in the case of the above need for the classification of disease and theories of liminality.

**Person-Centred Care (PCC), Validation and Reorientation**

Moving from the abyss of a social death and the over-medicalisation of dementia suggests that there is a clear divide as to what constitutes other modalities and the politics of care for persons with dementia. It is neither a clear nor an easy divide to transverse. As Locke pointed out, the ‘mobile target’ of dementia is constantly being discovered, rediscovered and contested. Locke also points out that it has become the epidemic of the 21st century, due to an ageing population and slow realisation that chronic illness will surpass infectious disease as the main cause of death globally by the year 2020; the vision is clear now, the world has a dementia problem. But costs are high and political will is low, as the carers fill the void of the state.

Dementia not only affects the mind and body, but also impacts family networks. It reinforces the unwillingness of people to give over to the state the care of their loved ones — and the state’s unwillingness to pay. Care for persons with dementia is like that of all epidemics; it hits people who are already exposed in ways that are harder and faster. Those without money, incomes, homes, families, networks and their health are more exposed to the symptoms of the state’s lack of involvement and over-dependency on people to do what is expected and anticipated. This is an uneasy situation that — over a short period of time due to migration, population decline and ageing — could tip the balance and force the state into action.

At the heart of how we care for people with dementia is how we see people with dementia. Post (2000) asks: ‘What picture shall we draw of the person with dementia?’ Is our view one of medical gaze? Are there alternative perspectives?

Kitwood and Sabat independently offered different perspectives of dementia in the late 1980s and early 1990s; both rejected the portrayal of ‘decline, decay and deficiency’ under the broad brushstrokes of the biomedical paradigm (Innes 2009: 11). For Kitwood, personhood is ‘a status or standing bestowed on one human being by others in the context of social relationship and social being; it implies recognition, respect and trust’ (1997:8). The self, accordingly, was derived and bestowed on the person with dementia through social interaction. This view can be traced back to Goffman and Mead who theorised that the self was based on social activity and interaction. Kitwood argued that through negative interaction with others, a person can be affected. Kitwood called this called Malignant Social Psychology (MSP). MSP ranges in severity from mild to severe. In this range, intent of the caregiver is essential; in other words, MSP can occur as a result of lack of knowledge to an action that is malicious. Kitwood is not without critics, and the implementation of his guide for carers is difficult as not only did Kitwood identify seventeen MSPs, but twelve Positive Person Works (PPWs) as well. Sabat argues that even
in severe cases of advanced dementia, the ‘person’ remains. Sabat categorised the self into three inter-related categories – namely, 1) the self as the singular self (the ‘I’), the attributes of the self, be they physical or mental – ‘I’m a good runner’, 2) the publically presented persona and 3) the roles in the context of relationships with others – the roles a person has, e.g., ‘I am a teacher, you are a student’. Sabat argues against the use of neurological testing to reveal incapacities; instead, the singular nature of the self is championed through singular observations and meaning-making behind behaviours attributed to symptoms of dementia (2005:10031). Meaning-making is central to the development of the three acts (in the play) that will be discussed later in the paper.

Kitwood postulated the view that everyday life for people without dementia was deeply pathological, (perhaps because of the banality and mundaneness of everyday life) whereas those with dementia become an exemplary model of interpersonal life which accordingly is the epitome of how to be human. People with dementia live in the moment or, more accurately, live in the moment of becoming, and Kitwood paradoxically suggests that people with dementia should be considered the more authentic self, true to the nature of humanity. The authentic self, accordingly, is derived from interaction. Freed from the pathology of everyday life, a person with dementia is more authentic.

Kontos, who wrote an ethnographic piece on an orthodox care home for Jewish women, argued that the self resists the disease progression because of the authenticity of corporeality. Drawing heavily from Merleau-Ponty, Kontos suggest that those with dementia will often act in the world at a primordial level through actions of the body. For Kontos, selfhood resides within and manifests through the ways of the body. While recalling the actions of one inpatient who was non-verbal, Kontos observed that they would spend their day stitching and knitting clothes. Kontos’s observations of selves within the ethnographic framework saw nonrepresentational intentionality – embodied self. The embodied primordial self is observable, present and not lost to dementia. It is no less than a socio-cultural and theoretical evolution that argues for the authentic self or the embodied self in the conceptualisation of the self in dementia. It is a counterpoint to theories of social death and medicalisation of dementia.

At the heart of these concepts and modalities of care is the dependence on informal care in Ireland. Caring for someone with dementia in Ireland averages fourteen hours per day. The unspoken truth about this level of care is that the state could not replicate it and that family members are often left with this level of care, irrespective of ability, training and the nature of the relationship prior to the onset of dementia. With over 60% of those with dementia living in the community, and with over 40,000+ living with dementia in Ireland, the hours of care provided by family and friends in Ireland are overwhelming.

What are the alternatives? In the U.S., for example, there is a greater dependency on institutional care, with an over-prescription on the pathology of dementia, and despite the universal call for PCC, institutional residents are tranquillised and the modus operandi of care is one of containment and control, be that pharmacological, environmental and physical restraint.

Equally contesting therapeutic modalities are reality orientation (RO) and validation therapy (VT). RO was the first intervention for people with memory loss, and not just for those with dementia. RO does not try to teach new skills; instead it uses cues, for example, time, date, weather and location. These were usually printed in large writing (in care homes). Staff and carers were expected to discuss these cues and prompts and were never to accept the other reality that may be offered by the
person with dementia. Systematic reviews have shown that the RO has conflicting results, with improvements in verbal orientation but little improvement in other behaviours (Bourgeois and Hickey, 2009:142).

Validation therapy has gained increasing recognition in recent years. Although piloted in the early 1980s, the idea of recreating a different reality for inpatients, either through dress or environmental change, reflects the growing distance between pathological treatments of dementia and socio-psychological modalities.

Validation therapy is credited to Naomi Feil as a direct response to RO. The VT premise is not to filter the reality of the person with dementia but rather to engage within the present reality. Another way of imagining VT is in allowing the human drama to unfold within shifting realities, regardless of whether those realities are spurious in the eyes of the beholder. VT also places a greater emphasis on non-verbal communication – for example, eye contact, touch and tone of voice. VT has not been scrutinised by systematic reviews, but there is positive anecdotal information suggesting that VT is commonly practised within informal care settings.

Dementia is a human drama, and it seems that the best way to respond is to allow it to unfold in the realm of human experience. It seems a mirrored logic that the care modality best suited to a disease that remakes or unmakes realities should allow realities to unfold in a human drama and, in turn, remake our realities. The theory is, regardless of the reality presented, that it is the emotional response that is important. Care of the emotions is greater than care of blended realities.

But, in reality, how can this message be conveyed? How do you interject at the critical moment where the carer is at in the caring process? How do you reach the already burdened carer who is overworked, unpaid and tired? Care is a human drama.

Forum Theatre and Boal

Augusto Boal is, perhaps, one of the most important figures in drama and drama philosophy and theory in recent years. His conceptualisation of theatre of the oppressed is universally celebrated. Boal’s theoretical and dramatic creations were borne out of personal persecution when witnessing the destructive drama of politics in South America in the 1970s and 1980s. His vision of theatre was deeply influenced by Aristotle’s philosophy, especially the nature of knowledge of – and human capacity for – vice, virtue and tragedy. His book, Theatre of the Oppressed (1979- later editions in 2000 and 2009), is a remarkable exercise in unifying the belief that politics is a social drama and that drama is a means of understanding social and political problems.

Boal was aware that actors, despite their best intentions, would interpret, for example, a social injustice through their own filter (life experiences) and, therefore, the representation of social and political problems would be false. From Boal’s point of view, theatre is a representation of human drama, and ‘theatre is change and not a simple presentation of what exists: it is becoming and not being’ (2000:16). Like Kitwood’s authenticity and Kontos’s primordial embodiment, Boal saw theatre as a means of stripping away the boundaries between stage and actor and reach an authenticity that mirrors life where stage and actor are contested and meaning and certainty are in a state of becoming – without answers. Boal’s view is that even outside theatre this holds true; for example, in drama, we see the tragic figure, observe their flaws and witness the critical moments that cause pain and demise. We empathise, and we see
ourselves in the drama – we are the drama, according to Boal.

Forum Theatre
Forum theatre is part of what Boal calls ‘theatre as language’. There are three stages to this – namely, simultaneous dramaturgy, image theatre and forum theatre. The last mentioned is what was chosen for the work with carers. Forum theatre (FT) is based on five stages: 1) a discussion of the issue (in this case, how to communicate with persons with dementia more effectively and avoid pressure); 2) actors portray the problem in scenes (this can be partially scripted or improvised); 3) the scenes are performed once more – the spectators (later described as spect-actors) can replace the actors and change the script in the context of the problem; 4) the actors play out new suggestions and 5) the joker (later described) reflects on the problem.

The Crystal Project Presentation
Over the course of six months, the Crystal Project Mallow (team lead by Sheena Cadoo) with the support of Alzheimer Society of Ireland began the slow process of developing a play loosely structured as forum theatre. With an open call, the Crystal Project was able to contact two actors experienced in forum theatre. These were Chrizine Blackhorse and David Ramseyer. Along with Amy Murphy (ASI), Cormac Sheehan set out to create and perform a three-act play for carers of those with dementia.

The structure of the play was simple. It was not to have more than three acts. The play was based on an imagined carer dyad (son/father) and played out over one day. The actors played out everyday events such as eating in a local restaurant, getting ready for bed and having an early-morning encounter. Each act was short (4-5 mins) and ended in an unresolved state, e.g., ‘Have it your own way’, ‘Stop acting like a child’ and ‘Who are you?’ These unresolved plays are what Boal calls anti-models, where the protagonist (in this case, the son) does not achieve his goals. Again, like the anti-model, dementia is an unresolved state as it is becoming, not being.

In these cases, the protagonist was the son – played by Cormac Sheehan. In Act 1, the son wanted to revisit the father/son relationship through the eating of dessert together in an old and familiar restaurant. The anti-model centred on the dementia; the father was unable to comprehend their reason for being in the restaurant. The second act depicted the son trying to get his father to go to bed and all the while trying to complete his own work. Again, this is an emotional time where agitation arises. The third act was when the son was at crisis point and the father, believing it was time for his children to be up and him off to work, began cooking at 4 a.m. The son, bewildered and angry, just wanted his father to be in bed; did not want to have confrontation or cause injury to himself; and didn’t want to damage the house. The plays were performed for group of carers; there were fourteen at the first performance, eighteen at the second and then fifty carers (not specifically carers of people with dementia) at the third.

Act 1 (Abridged) – 3p.m. in a local restaurant
‘This is nice.’ (Steven= S) ‘I never liked this place.’ (Dad= D)
‘What are you talking about? You love this place – remember, we used to come here all the time.’ (S)
‘I don’t like it here ... I want something proper to eat.’ (D)
‘What! We just had dinner before we came; we will just have dessert, I’ll call the waiter.’ (S)
‘No! I want to have something proper.’ (D)
‘You did; we had roast chicken, roast potatoes and all the veg before we came.’ (S)
"I want something proper... Oh look! There is my friend, John. We used to play football together... I will go over and say hello." (D) ... gets up and walks over towards John

"Jesus Christ!" (S) ... mutters under his breath, rubs his face and gets up after his dad

"Dad, what the hell are you talking about? That is not John; that man is the same age as me." (S)

"It is him, I'll just go over and say hello." (D)

"Dad, for God's sake ... will you ever sit down? These people here are trying to eat and you are embarrassing them ... just sit DOWN." (S)

"Oh! ... very well." (D) ... both sit down

"You always want to have it your OWN WAY!" (D) ... slaps the table

Act 2 (Abridged) – 10p.m. upstairs in Steven’s house.

"OK Dad, it is time to go to bed." (S)

"I don’t want to go to bed. What are you talking about? What time is it? You know me, I’m a night owl. I think I will go and read the paper." (D)

"Not this again, it is 10p.m. You have to go to bed." (S)

"I’m not going to bed. You do your thing ... and, remember, I have to go to the bank in the morning. It is very important." (D)

"Just go in and get into your PJs, they’re on the bed." (S)

"PJs, what am I, a child?" (D)

"Come on ... I will give you a hand." (S) ... tries to unbutton his father’s shirt

"Don’t treat me like a child!" (D)

"Well, STOP ACTING LIKE ONE." (S)

Act 3 (Abridged) – 4a.m. in the kitchen of Steven’s house

"Steven! It’s time to get up and go to school." (D)

"Dad ... what are you doing? It is 4 in the morning ... you will burn the place down." (S) ... as he turns off the cooker

"Come on and get the others up. I have a busy day today ... and get your mother up, I don’t want to be late and I don’t want you to miss school." (D)

"What are you talking about? Mum died ten years ago, and you live with me now, remember?" (S)

"I don’t know you. Who are you? I don’t know you." (D)

"I am Steven, your son." (S)

"Get away from me. Who are you anyway?" (D)

Part of Boal’s theatre-scape is the spect-actor. The ‘spect-actor’ challenges this mono-logic approach and functions to “democratize the stage space—not to destroy it!—rendering the relationship between actor and spectator transitive, creating dialogue, activating the spectator and allowing him or her to be transformed into the ‘spect-actor’” (Boal 1997: 67). Keeping the process together is the Coringa or Joker. The Joker has multiple roles: actor, master of ceremonies and spect-actor. In this case, the Joker was also responsible for drafting the scripts for the acts. For Boal, the Joker should be critical; he/she can interject in acts and stop the action. Boal described the Joker as a ‘difficultator’ – not a facilitator. The Joker is there to question easy answers and the realism of the unfolding drama. The Joker must obscure the easy paths to resolution of the anti-model. The role of the Joker is very important, demands a balanced point of view and must push the actors and spect-actors without losing sight of their limits and the aims of FT.

Like Feil’s development of VT as a response to RO, Boal’s theatre of the oppressed challenged the form, space and dynamics of traditional theatre. Pushing against the prescribed outcomes of theatre, Boal created a theatrical revolution in the context of revolution in 1970s South America. ‘...the destruction of barriers created by the ruling classes. First, the barrier between actors and spect-actors is destroyed; all must act, all must be protagonists’ (Boal 2000: xxiv).
In this case, each act showed the person with dementia becoming increasingly confused and agitated as the day progressed and the carer becoming more annoyed and consumed by the pressure of caring for their father. It was a reasonable representation of the life of the carer dyad. Amy Murphy, who is the dementia advisor for ASI (Munster), and David (actor and carer) helped create the nuances of the three acts. The son was the protagonist; he was virtuous, but full of vice. His vice was to relive or, perhaps, revive the past. He wanted to return to the traditional father/son relationship whereas the father was moving through different realities, e.g., seeing old friends, wanting to go to the bank in the morning and getting ready for work. In the end, he was unsure of who his son was, where he was and when he was there, leading him to cry out, ‘Who are you?’ Indeed, dementia can also be understood as the protagonist. If Kontos and Kitwood are correct, dementia – as grounds for the authentic self – is virtuous, and the vice is the resulting actions because of that authenticity.

Validation, Empathy and Knowledge

The spect-actors who attended the first two performances were experts through experience in dementia. They engaged with the play – some eagerly interjecting, raising their hand to stop the play. Others would not come and take the role of Steven, and the actor replayed the part under the instructions of the spect-actors.

The first outcome from the acts was that all of the spect-actors’ interjections can be understood in terms of the validation of the realities of the father. In Act 1, for example, the spect-actors came up with various ways to allow the father to be content and to disregard the reality that they already had eaten dinner; here, the spect-actors suggested that he should be allowed to eat what he wants to, suggested the two of them going for walk and asking the waiter in the restaurant if they could have the food to go. In Act 2, the spect-actors responded – as the father became more agitated – by interjecting and stating that there was no need to force the father to go to bed, suggesting that they watch TV together or read the paper together. Others suggested that the reality for the son was crucial as he was trying to finish his work. But instead of forcing the father to go to bed, they suggested inviting him to help with his son’s preparation for work.

In the final and climactic act, the spect-actors interjected and emphasised that they should sit down and eat together, allowing for the father to come to terms with the present reality. One spect-actor suggested forgetting about the reality and engaging humorously with the father – e.g., ‘What are you doing? was replaced by ‘What are you doing, you know you make terrible eggs?’ and ‘You do the tea...if you can find the kettle.’ The subtlest validation!

The feedback was overwhelmingly positive from a carer’s point of view. The learning was poignant, and it was clear they had been in the position of Steven before.

The second outcome was the empathy towards the son. I (Cormac Sheehan) played the son and engaged with the character to the best of my novice ability. I tried to become as agitated as I could... even to the point that when the Joker asked me to stop and speak my mind, I said: ‘I feel like I’m going to kill him’ – I did feel that way. Like Boal’s awareness of the cultural filter of actors, my filter was based on my own experiences of having children and the frustration and annoyance which seem to be boundless. But all the spect-actors, regardless of my agitation and frustration, displayed empathy. Empathy is bound in the dramatic representation of a character’s ethos – what a character does – and the dianoia, i.e. the motivation for action. In this case, the hamartia or character flaw or vice was the son’s attempts to recreate a father/son bond; clearly, this was impossible.
when his father was moving in and out of different moods. The spect-actors were able to create new bonds based on the father’s new realities. The spect-actors empathised with the son many times – ‘he has work, he has a family, he has young children’, they said. They were right, both for Steven and me.

Knowledge in the context of dementia is a driving force in the conceptualisation of the self and the move towards PCC in the modalities of care. Kontos argued for primordial embodied knowledge, and this position is evident in the large body of literature on the processes of remembering through consolidation and emotional memory. Sometimes, we can take action and our embodied knowledge is what we depend on. In the case of our spect-actors, their knowledge of care was rooted in real world experience. All would have recognised the issues – of public embarrassment, trying to get someone to go to bed or night time wanderings.

Boal is concerned with how knowledge is used within theatre structures. Boal (drawing from Aristotle) argues that knowledge has to be present if a person is to be held accountable for their actions. In the case of dementia, knowledge is central, and the onus is not on the person with dementia but on the carer. As the person without knowledge is unable to comprehend, they cannot be held accountable and, therefore, their ethos and reason can be overlooked. It’s a small solace for the spect-actors and the thousands of other carers. Perhaps this is why that until a diagnosis of dementia is present, resentment, difficulties in relationships and breakdown of communications can often be present in a pre-diagnosis phase; the marginal space of non-diagnosis in the context of dementia can be a very lonely and confusing space. For the spect-actors, as they showed empathy to Steven, they showed equal patience and acted out practised routines tied to their realities. Knowledge and removal of blame are central in the care of a person with dementia. However, Gubrium (1991) offers a different point of view of knowledge and describes care as a mosaic with many possibilities. Are all actions of a person with dementia caused by dementia? Equally, are all actions of carers – which may lead to MSP – caused by demands of care or are they attributable to outside pressures? Care, as expressed by the spect-actors, reflects all the colours of human drama.

Concluding Remarks

Dementia and the care for persons with dementia are still in the stage of becoming, with competing modalities and philosophies of care. FT, as an art form, reflects this unscripted state of becoming and has been shown here and elsewhere to be an effective medium. At the heart of the pressure play was the nature of human interaction whereby the son showed virtue and vice in the anti-model and where the spect-actors showed empathy for the son and validation of the father’s emotions.

It is possible to suggest that VT is best suited to the care of people with dementia as it mirrors the nature of dementia. In the process of caring, carers have to perform not only daily tasks of routine and banality, but also act out different realities. It is a demanding role.

Boal, (again drawing on Aristotle) argues that nature strives for perfection. However, nature does not always attain perfection. The nature of human beings is flawed; humans are characterised by illness, such as dementia. In an Aristotelian frame, dementia is flawed in nature, but nature can be corrected by using ‘suggestions from nature itself’ (2000:11). Art imitates nature or, more precisely, art is ‘re-creating the creative principle’ (2000:10). Dementia is a fault in nature, whereby realities are uncertain and memories change. In the case of dementia, understanding
changes, faculties change, reality changes, memory changes … and by taking those faults of nature as suggestions of what to do, it is possible (for, perhaps, short periods of time for a carer) to help maintain a person ‘as they should be’. Caring is not just something people do; it is an art form that tries to fix the faults in nature.

If we left carers to their own devices, would they begin with resistance and fight the dementia, and then arrive at the conclusion that dementia takes away in part the pathology of everyday existence which leaves a person as the authentic self in ever-changing realities? As the spect-actors showed, all they could do is hold on and step into the ever-ebbing-and-flowing realities of the people they care for so deeply.

References


ARTICLE

THE PROPRIETY OF THE NORMAL: CHILDBIRTH AND RISK MANAGEMENT IN IRELAND

BY SANNA POELMAN

Abstract: The purpose of this article is to present an anthropological understanding of how risk is managed in childbirth by focusing on two comparative standpoints, the Irish State that provides maternity care services and the women that opt for a home birth. Through conducted ethnographic fieldwork in Ireland, this research shows that Ireland's health care institution applies a technico-scientific approach to risk, where risk assessment is based on objective, calculable criteria that are supported by science and expert knowledge. In the case of women choosing to birth at home, risk is subjectively perceived through aesthetics and hermeneutics and is based on personal and other's life-world experiences, emotions and intuition.

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Introduction

On a grey Sunday morning in the spring of 2014, I took the Luas from O'Connell street to an industrious suburb in Dublin to attend a home birth conference organized by the Home Birth Association (HBA) of Ireland. Not having had much time to deepen myself into the topic beforehand, and with no prior ethnographic fieldwork experience, I was quite nervous when I entered the mid-size conference room of the hotel, filled with women and men, both single and married, professional and lay attended by children of all ages. My aim was to get a pre-liminary sense of what was being discussed surrounding the topic 'birth', and I was especially interested in why these people opted for a home birth in Ireland.

Before continuing, I want to introduce this paper. This paper, which I presented at the Caring Cultures/Cultures of Care conference (AAI) in March 2016 in Maynooth, Ireland, is a summarized version of my master's thesis, and part of my master's degree in social anthropology at Stockholm University, Sweden. The title of the thesis is "The Propriety of the Normal: Childbirth and Risk Management in Ireland" (2015) and the text looks comparatively at how risk in childbirth is perceived and mitigated from two different angles, namely from those that opt to give birth at home as well as from a state perspective. By looking at the concept 'risk' in an anthropological manner, one can detect that the term has different meanings, and as follows, different consequences depending on the standpoint inhabited.
To come back to the home birth conference mentioned above, what these proponents of home birth were arguing for (and against) was that a woman should have more control over her body and birth in a hospital context, referring strongly to their human rights in childbirth, and criticized the dominating role of insurance policies in relation to risk aversion as well as the medicalization of childbirth in contemporary Ireland. With these notions open for debate, these advocates considered home birth to be the only way to attain a kind of birth that they so much desired and pursued for.

With getting a pre-liminary answer to the question: why do some women in Ireland want to give birth at home, I decided I wanted to find out more about this topic, a decision that resulted in a return to Ireland later that same year for a six-week fieldwork session. The data collected came into existence through a snowball effect, as in I talked to one midwife, who knew some mothers that were actively advocating home birth, who again knew someone else, and so on. I was also able to talk to some mothers from the HBA and my request for research participants was put in their newsletter. Finally I was able to attend three home birth support meetings, where I sat among other querying participants, ate cookies, drank alcohol-free gluhwein and tried out birthing pools.

Annually there are around 250-300 home births in Ireland (data concerns year of research, 2014), which are carried out through both publicly and privately funded channels. A publicly funded home birth is provided by the Health Service Executive (HSE) to women that are categorized as low-risk throughout their pregnancy and that live in certain geographical areas where the service is provided. Despite the fact that home birth is part of the national maternity care service, many of my research participants stated that home birth in itself is hardly supported by the HSE, and was according to some even strongly discouraged, because some doctors "did not believe in it". To be able to understand this statement, I included into my thesis a comparative approach: the first analysis chapter deals with how the Irish state, and especially the HSE, understands 'birth' and the risks that it involves including the possible adverse outcomes and the second analysis chapter looks at how women that opt for a home birth perceive childbirth risks and describes how they minimize and mitigate these risks subjectively.

Applied Theory

The title of my thesis invites the following question to be answered: what is normal for whom and in which context? To be able to answer this question in relation to childbirth and risk, I applied Brigitte Jordan's (1997) theoretical notion on authoritative knowledge. According to Jordan, authoritative knowledge is a kind of knowledge that is considered within a particular social-cultural context as normative, natural, superior and reasonable, and upon which justified decisions are made (Jordan 1997: 56-58). This knowledge system is not necessarily authoritative because of its implementation by people in authoritative positions or because the knowledge is ultimately correct, but because of its widely accepted accountability derived through the interactions among people on all levels of society (ibid.). To put it simply, authoritative knowledge defines what is 'normal' in a particular social context.

To understand the perception of normality in relation to the human body, I found Lock and Nguyen's book An Anthropology of Biomedicine (2010) elaborative. The authors discuss the issue of normality broadly and
argue that in Western biomedicine 'a normal body' is a statistical average, a norm, which is to be attained to be classified as healthy. When deviating from this statistical average, the body is no longer considered as normal, but pathological and in need of intervention, supervision and control. The basis for this average is the perception that the human body is a universal unit, possible to be calculated, resulting in processes of standardization. This perception of normality then not only defines who and what is normal or abnormal, healthy or unhealthy, but also how the body *ought* to be, the norm. (ibid.: 32, 39, 44, 45)

When it comes to defining what is normal in childbirth, it depends on the standpoint one takes when looking at this social and physiological phenomenon. In Ireland and in the Western hemisphere at large, the normal way to give birth is in a hospital context, where medical expertise and technology is at close hand when something goes wrong. Here childbirth, looked upon through the medical model, envisions childbirth as an inevitable risky condition to be in and is considered "normal only in retrospect", meaning that the birth can only be classified as normal afterwards, when nothing has gone wrong. Pregnancy and birth are then in itself considered pathological conditions to be in, and in need of a medical cure carried out by medical experts to retain a body of normality once again. (MacKenzie Bryers & van Teijlingen 2010: 490-491)

With a hospital birth considered to be part of the medical birth model, a home birth is understood through the social birth model. This model understands birth as a natural and normal, physiological event, that needs minimal external intervention and/or guidance (MacKenzie Bryers & van Teijlingen 2010: 490). The pregnant woman is looked upon in a "holistic" way, with her being seen as a "social, emotional, [and] physical entity" with both "a past and a future and as part of a larger social structure" (Kennedy 2002: 17). Values that prevail in the social birth model are the home context, the attending, securing midwife, and the experience of empowerment for all attendees during birth. Besides this, intuition, experience and emotional relationships are considered highly important, while control of the birth process is placed in the hands of the labouring woman. (MacKenzie Bryers & van Teijlingen 2010: 490-491)

The hospitalisation of birth in Ireland dates back to the 1930's, and home birth as a birthing option started its decline in the 1950's. However, it was not until the late 1960's that the hospitalisation of birth got its prominence with the introduction of the active management of labour-model by O'Driscoll and colleagues in the National Maternity Hospital in Dublin. The aim of this model was to shorten the labour process of first time, non-progressing birthing mothers possibly experiencing mental and physical stress, by inserting a range of clinical and medical interventions to speed up the birthing process. (Kennedy 2002: 18, 60, Pates & Satin 2005: 222, 227) Currently this model is applied in different degrees and with different emphases in the Irish maternity units, and according to one of my research participants, a professor in midwifery in one of the colleges of Ireland, "one hospital says it does the act of management, but anyone else does it, half does it, does not really know why it is doing it, [or] does not follow it right", showing the level of ambiguity surrounding this "philosophy", as some scholars have named it (e.g. Kennedy 2002).

To relate the concept of 'risk' to the discussion of (ab)normal bodies and childbirth, sociologist Deborah Lupton provides an interesting perspective. In her
chapter Risk and the Ontology of Pregnant Embodiment (1999b), Lupton states that when looking through a biomedical perspective, a pregnant woman is considered a 'living risk' due to the embodiment of two subjectivities in one human body, an aspect that is incomprehensible for the human rationale and "beyond social control". A pregnant body is understood as an abnormal entity, classified through notions of risk, which leads to justified measures of medical control, supervision and potential intervention. (ibid. 61, 63, 68, 78, 79) As both Lupton (1999b: 66) and MacKenzie Bryers and van Teijlingen (2010: 492) argue, there are no "zero risk" pregnancies and births, and the pregnant woman and foetus are constantly at risk for further harm.

The notion of being a living risk is also detectable in the Irish maternity services. For example to be able to opt for a birth at home, one needs to be classified as a low risk pregnancy (the other option is high risk), a risk assessment procedure that is based on a list of more than 50 risk factors and that is valid throughout one's pregnancy. These factors are ranked in their severity, with some definitely declining a woman a home birth, while others requiring additional check-up(s) from an obstetrician before proceeding. (Health Service Executive 2013)

One may ask, why all this control? A simple answer could be, because of possible negative or adverse outcomes. Mary Douglas wrote on this subject in her book Risk and Blame (1994) and argues that risk has become part of our everyday thinking and actions and every institution, corporation and individual is aware of possible liability claims and malpractice issues. The author emphasizes that risk has become "endemic and self generating" and as an example she gives the interaction between doctor and patient, which according to her has become "formal and distant", with much of the information consisting of objective probabilities produced in a written form. (ibid. 14)

When defining what is a risk and what not, sociologist Roy Boyne (2003: 64-65, 75-76) emphasises the process of 'problem framing', and argues for the social embeddedness of established risk factors. The author states that there are no neutral, objective risks that exist universally, but notes that risks are created within in a particular socio-cultural context of which they can be seen as a characterising element. (ibid.)

To understand the connection between normality, the birthing body and risk management, I believe that Jordan's (1997) notion on authoritative knowledge is of significance. For depending on which knowledge system one deploys, normality in relation to the body and the risks involved can have several meanings, and as a consequence, a large range of preferred measures and desired outcomes. However, Jordan states that some knowledge systems have more "weight" than others, "either because they explain the state of the world better for the purposes at hand (efficacy) or because they are associated with a stronger power base (structural superiority), and usually both" (Jordan 1997: 56) When looking at childbirth in Ireland, the applied medical model can be identified as part of the authoritative knowledge system, because of its several decades long tradition of birthing in hospitals (efficacy) and because of the role of the Irish state in providing national maternity care system (structural superiority). Thus as already stated above, the normal way to birth in Ireland is in a hospital setting with medical care and professionals present, a setting that for many remains unquestioned and the only option possible. As a consequence, the social model in which home birth is embedded and which prevailed before
the hospitalisation of childbirth 'weights' less than the medical model, making it an abnormal option to opt for.

With the above in mind, the research question that I aimed to answer in my master's thesis is: how is risk managed in both a hospital and a home context by the actors involved and what is the role of (authoritative) knowledge in these practices?

A Perspective from Above

Due to my limited fieldwork time and capacity, I was not able to interview state officials and medical professionals or observe at an Irish labour ward to inquire on risk management during childbirth. However, when going 'through' the website of the HSE, I found policy-making to be of importance regarding how large institutions are managed, including potential risks and their adverse events.

To understand policy-making in an anthropological manner, the book *Anthropology of Policy* (2005) from Cris Shore and Susan Wright is insightful. In this book the authors scrutinize policy-making as a concept and state that "policies are inherently and unequivocally anthropological phenomena" because of their organizational dimensions within a particular socio-cultural context. (ibid. 5, 6) They continue that policies often remain unquestioned because of their presumed neutrality, rationality and objectivity resulting in that they are hard to oppose or criticize. However, Shore and Wright emphasize that in policy-making there are always power structures at play which promote certain values and norms over others and that inherently have an impact on how people experience themselves and their everyday lives. This results in a way of governance that does not necessarily come from 'above', but that is acted out as "a type of power which both acts on and through the agency and subjectivity of individuals as ethically free and rational subjects". (ibid. 3-5, 6, 7, 9)

With keeping in mind that policies function as a mode of governance, I analyzed a range of HSE policy documents that were available online to get an understanding of how the HSE is governed. What was interesting to note is that these policy documents provide guidance and practical guidelines for how certain situations ought to be dealt with and what kind of behaviour is preferable to avoid negative outcomes. To give an example, in the policy document *Codes of Standards and Behaviour* published by the HSE, it is stated that employees should act according to the "philosophy" of the HSE, which endeavours certain norms and values such as impartiality, loyalty and honesty. According to the HSE, this policy "sets out a clear framework within which employees must work" and it represents "in a single document the principles which should govern the behaviour of employees and the values which the HSE espouses." (Health Service Executive, Codes of Standards and Behaviour)

Shore and Wright (2005: 14) state that one way to analyze policy documents is to look at its language, and the authors emphasize the importance of keywords for getting an understanding of the prevailing discourse. When going through the 96-page-long *Code of Governance* (Health Service Executive 2011a), a policy document that describes HSE's corporate governance enacted through a range of standardized procedures, protocols and norms, I calculated in it the word 'audit' circa 280 times, 'risk' 110 times, 'standard(s)' 90 times and 'best practice' 36 times. Shore and Wright (1999) have previously analyzed the concept 'audit', which according to the authors contains similar implications as
'policy' does. For example, with the rise of the audit culture, emphasis is laid on personal aspects as self-empowerment, responsibility and accountability, while keywords such as 'management', 'best practice' and 'efficiency' are predominant. Shore and Wright argue that audit cultures have great implications, since being based on a system where rewards and punishments prevail, an atmosphere of self-monitoring, enhancement and improvement is produced, with internal and external controls and evaluations to enhance accountability. However, just as policy, audits contain a level of neutrality and objectivity resulting, according to the authors, in "no logical reason for objection". (ibid. 557, 559)

The first audit regarding maternity care service in Ireland was carried out in 2013, which was concluded with positive results. (The Cork News 2013) However, in the coming up year it became nationally known that several babies had died in one maternity unit in Ireland, while a pregnant woman had died during medical care in another, which resulted in a national outcry to improve maternity care services. As a response, the HSE reacted by stating that "every hospital should have a formal system of audit of pregnancy outcome on a monthly basis" (RTE June 2015), while ten recommendations were given to enhance the quality of care given at maternity care units (Irish Examiner 2015).

Something that can be seen as intrinsically linked is the connection between quality care and risk management. This aspect can be found in HSE’s policy document Quality and Risk Management Standard (2007), where the following Statement of Standard is given: "Healthcare quality and risk are effectively managed through implementation of an integrated quality and risk management system that ensures continuous quality improvement". (ibid. 5)

What is interesting to note is the way 'risk' as a concept is perceived in the HSE. A definition is given in the document Risk Assessment Tool and Guidance (2011b), where the HSE defines risk as following: “the chance of something happening that will have an impact on the achievement of organisational stated objectives" or "the effect of uncertainty on objectives” (ibid. 3). To be able to estimate the occurrence and frequency of certain risky situations, the following questions are posed: "how likely is the risk to occur?" and "how frequently has this occurred?". (ibid. 4) By employing an "HSE-wide, standardized approach to the assignment of likelihood and impact", it is possible to collect data through a 'likelihood scoring' and 'impact scoring', both ranging from 1 to 5, and which are then put into a Risk Matrix to determine its severity. Based on this, the HSE decides whether the risk will be accepted by determining its severity as minimal or outside the control of the HSE, or to be treated by either avoiding, transferring or controlling the risk. (ibid. 4, 6, 8, 9-10)

So what happens if something goes wrong? At this stage the State Claims Agency (SCA) steps in, a state institution that assists in risk management protocols and deals with litigation claims made against the Irish state. As the SCA describe themselves on their website:

"Where claims do arise our objective is to manage these claims so as to ensure that the State's liability and associated expenses are contained at the lowest achievable level." (State Claims Agency 2015a)

Having to cover a "risk universe" (as the SCA names it) of more than 200,000 state
employees plus the subjects that make use of public health care services, the SCA employs a risk management team consisting of professionals with backgrounds in science and engineering for producing risk information, including solutions and measures, to prevent potential costly negative outcomes. (State Claims Agency 2015b) Lupton names this kind of approach to risk a "technico-scientific" one, where "objective phenomena" are "predicted and controlled via science and expert knowledge", and which can be seen as part of the "hegemonic model of risk". (Lupton in Chadwick and Foster 2014: 69) Douglas has argued that to be able to get the most objective and neutral perception of potential risky situations, risk experts leave out the "human factor", such as personal motivations or political commitments, resulting in that human beings are simply understood as "hedonic calculators" that have "the same responses and preferences" everywhere. (1994: 13)

A perspective from below

Something that both Lupton (1999a, 1999b) and Douglas (1994) emphasize, is that there may be a clear discrepancy between what experts consider a risk and what lay people perceive as risky. At this stage, I want to move to the second section of my thesis, namely to how women subjectively experience risk in childbirth, and especially when they opt for a home birth in Ireland.

Besides the reasons mentioned at the home birth conference listed above, my research participants explained their choice for a home birth as following: e.g. fear of losing control in a hospital setting, mistrust towards medical experts, the loveliness of the home context, family traditions, the importance of a home birth for the father, the presence of one's children at birth, the absence of medical interventions and experiences of empowerment. What was interesting to note was that one of the worst possible scenarios for these women was the thought of having to go and give birth in a hospital context, where the active management of birth-protocol is applied. As one woman told me:

There is a girl down the road who gave birth [in an Irish hospital] three weeks ago, and she said that there was a change, and she was doing fine and then there was a change in midwives and she lost her focus during the labour. She said she lost her focus and couldn't get back into her zone, she completely lost it. And she was in the hospital, so she said, give me the epidural! Because she knew it was there. But she was doing great and with the epidural she had to have directed pushing, so she had to be told when to push, and she was pushing, and the baby, her head was out, but the shoulders were not fully turned and she was directed to push, so she pushed and she tore from front to back. She was up in theatre having herself stitched up again. ... [But] her stitches got infected and so she had to go back into the hospital and she had to go on antibiotics. And it is all because of an epidural! (I)

To understand this narrative, I thought Lupton's arguments to be helpful. She (1999b: 70-71) states that the way pregnant women in Western societies experience childbirth risks has a lot to do with the socio-cultural context in which they are located and the way women personally understand pregnancy and birth. What is emphasized is that not only do women retrieve objective information regarding birth from medical experts, but also take into account intuition, bodily changes and personal and other women's life experiences, to configure what birth would be like and the potential harms it could entail. Lupton continues that it is subjectively experienced 'aesthetics' and 'hermeneutics'
that give form to childbirth perceptions, responses and desires, including the risks it involves. (ibid. 76-78)

To understand how these women perceived childbirth risk in my analysis, I applied MacKenzie Bryers & van Teijlingen's (2010: 489) definition of 'risk': "the possibility of unintended and negative consequences of decisions and actions". Based on this definition, it can be concluded that for the women in question, the biggest risk they encountered was the possibility of having to give birth in a hospital context. This fear was quite realistic, since the majority of the births happen in a hospital context, making it the norm and something that is most commonly promoted. To control this risk, the women applied a range of strategies and measures that would secure their home birth, such as finding the 'right' general practitioner (GP) that would sign them off as 'low risk' to be able to opt for a home birth and by finding a home birth midwife as early as possible. Some other risks that were mentioned were labour pain, including tearing, and mental well-being (e.g. depression), which were managed by attending hypnobirth and yoga sessions to stay strong during the birth process; by befriending 'similar others' at home birth support meetings and conferences to "feel normal"; and by becoming informed by collecting both physiological and institutional data regarding childbirth in Ireland.

Kirsi Viisainen discusses in her text The moral dangers of home birth: parents’ perceptions of risks in home birth in Finland (2000) three kinds of risks that were acknowledged by home birthing parents in Finland: 1) "medical risks of pregnancy and birth", 2) "iatrogenic risk of medical practice" and 3) "moral risks of going against medical authoritative knowledge". What is interesting to note is that while both medical risks of pregnancy (childbirth in itself as risky) and iatrogenic risks (practiced medical care in childbirth as a risk) were acknowledged by my research participants, they also had to deal with moral risks when it came to their choice for a home birth. What is meant with moral risk, according to Viisainen (2000: 794), is that women opting for a home birth take on the risk of going against the authoritative medical discourse on childbirth, possibly resulting in having "to deal with the moral danger of labelling and stigma consequent to their 'irresponsible' behaviour".

Similar experiences regarding moralization could be detected in Ireland. For example one woman told me how she had gotten "a lecture" from her GP, where "he said that he would treat me the same way as I would've had an abortion. He thought I was being so irresponsible.." (G). In relation to stigmatization, the term 'hippie' was used both by the women themselves as well as by others to describe someone that wanted to have a home birth. While one woman noted, "I think everyone thinks that a home birther is a hippie and who is not gonna bring their kid to the hospital if they're sick" (D), another stated that "there is a bit of an angle that they think we are a bit hippie, a bit alternative and irresponsible" (G). Viisainen (2001: 1117) notifies that "there would be no 'alternative' if there was no standard", a statement that opens up the debate on what can be classified as normal and what not. As one woman contemplated:

Maybe it is my parenting style, it would be quite different, I suppose it kind of all goes together, like I would always wear [my child] in a sling, and breastfed, and she slept in our bed with us. You know, whereas most people, in the 'normal' world that is, they think I am mad, absolutely. Like I am making it hard on myself, I need to go on nights out, I should to give her the bottle, I should have finished
breastfeeding at six months at the latest. (...) And because I suppose that is not that normal, you try to look what is, and that is when all this kind of stuff becomes normal. (N)

Conclusion

What I aimed to show in this article is how childbirth and the risks that it contains can be understood in different manners depending on one's standpoint. With the question: what is normal for whom and in which context? in the back of my mind, I looked at how the Irish state, and more specifically the HSE, governs its risks by employing a multitude of policies through which its "philosophy", including its dominant risk management protocol, is institutionally enacted. By using a technico-scientific approach, risks are objectively established, cross-sectionally standardized and numerically scored, to determine their severity and the best manner to deal with them. Childbirth, understood through the authoritative medical birth model as an inherently risky condition to be in, needs to be regulated and supervised by medical experts in a hospital context and is normal only in retrospect when nothing has gone wrong.

The women that opted for a home birth perceived birth to be a normal, physiological condition to be in, with one telling me how she loved being in labour (K), while the other emphasising that she did not feel at risk at all while giving birth (I). In relation to this, Lupton (1999b) argues that personal and other people's experiences, intuition and emotions play a great role in how pregnancy and birth are experienced, including the potential risks and adverse outcomes. With home birth being part of the social birth model, the domicile context and midwifery expertise are much appreciated and comforting, while feelings of empowerment for all birth attendees is encouraged throughout the birth process.

By looking at the above mentioned perspectives, I aimed to elaborate the propriety of the normal. What this statement means is that depending on the knowledge system applied, normality can have several meanings and as a consequence a range of suitable measures, actions and behaviours. However, depending on the 'weight' of a knowledge system, one tends to dominate/overrule the other, resulting in that both normal and abnormal get their significances subscribed within a particular socio-cultural context.

References


Online resources


nd_Patient_Safety_Documents/riskoctober.pdf


Notes
ARTICLE

‘COMMUNITY HEALTH IN ACTION’: NOT A THEORY-FREE ZONE

BY SORCHA NÍ CHRUALAOICH & GEARÓID Ó CRUALAOICH

Abstract: In unpacking, theorising and reimagining Care and Caregiving - it may be appropriate to view Community Health Project work of the kind outlined here against an extended theoretical framework drawing on a variety of anthropological concepts. Altruistic ‘caring’ actions accompanying such delivery of healthcare in community based settings, whether through formal or vernacular agencies and activities, can indeed strive to constitute, in Kleinman’s terms, a ‘moral experience’ to the benefit of both parties to the caring transaction.

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Introduction

The Cork Northside Health Action Zone (HAZ) programme is a partnership between the HSE and local communities focussing on the development of sustainable community health initiatives within areas of high disadvantage on Cork’s Northside. It aims to identify and address barriers to care services access and to develop strategies promoting the delivery of health services in the community. Each area employs a Community Health Worker who works closely with a Local HAZ Advisory Group in identifying needs and responding to them.

The Health Action Zone programme was mainstreamed just over 10 years ago within the HSE Community Work Department whose core work is Community Development and Social Inclusion with a focus on health equality. The formal delivery of healthcare in a community based setting must constantly recognise the tension that goes with the instrumentalisation of altruism and deal with the conflict between bureaucratic organisation and the gift-like provision of care.

In analysing and reimagining the concept of ‘care’ an initial consideration can be that of caregiving as altruism. Altruistic ‘caring’ actions accompanying such delivery of healthcare in community based settings, whether through formal or vernacular agencies and activities, can indeed strive to constitute, in Kleinman’s terms, a ‘moral experience’ to the benefit of both parties to the caring transaction. (Kleinman 2012: 1550-1) Caring in this perspective is to be understood as a foundational element of human experience regarding meaning and practise since it can be understood, fundamentally, as a basic human response to
the perception of great need. The verb ‘to care’ derives from a root meaning ‘to cry out’, to lament’, to grieve’ and it is in this sense that we can understand the correctness of Kleinman’s characterization of caring as moral action and experience.

Such moral action in the interest of others is, essentially, an altruism that, as a principle of morality, contrasts with an egoism that Kleinman sees as informing the economic paradigm that too often underlies bureaucratic, instrumentalised ‘caregiving’. The term ‘altruism’ – coined by August Comte – derives from the Italian altrui ‘someone else’ and altruistic caregiving will, in this light, always include a Gift-like reciprocity (akin to love) that does good for the giving/caring Self as well as for the receiving/cared-for ‘Other’. Thus ‘The Good Samaritan’ is transformed into ‘A Better Samaritan’ as a consequence of properly altruistic Caregiving that acknowledges the Personhood and affirms the vulnerability and struggle of the disadvantaged and the distressed.

In a setting where the work is underpinned by Community Development Principles, Caregiving necessarily implies the promotion of Personhood in the face of disadvantage and exclusion and comprises the pursuit of a distinctive vision in the midst of the political and economic realities with which care-giving is inevitably entangled. The realisation of such a vision requires a strong basis in anthropological method.

Aiming for a theoretically enlightened integration of Community and HSE effort, The Health Action Zone and its Community Health Workers proceeded – through dialogic fieldwork – to further identify and explore the needs of and the barriers to healthcare within communities of chronic disadvantage on Cork’s Northside.

A process which had begun via a Community Consultation process and the development of community profiles by the HSE and community partners was handed over to the Community Health Workers to employ their various forms of expertise – (both academic and that arising from prior community experience) to carry out fieldwork and engage practically with the community as a whole. This involved such issues as:

- the negotiation of access to community settings, to community groups and key individuals and to local knowledge.
- a sensitivity in regard to local history, current community demography and area deprivation profiles, local politics and power relationships.
- the exclusion of bias – in so far as no Community Health Worker worked in the same area as that in which they lived.

Using a holistic definition of health, they collected their data at a variety of venues such as; local BINGO, a Women’s Group meeting, venues where young people ‘hung out’, local sporting events, at school gates etc. The Community Health Workers interpreted what they found and, out of this, developed ideas regarding practical responses to the health needs of the community - in collaboration with local people and key front line HSE staff.

A key vehicle for providing local information and for assisting the Community Health Workers in interpreting and responding to their ethnographic findings was the local HAZ Advisory Group - comprising HSE front line staff (Public Health Nurse, Community Welfare Officer, Community Worker, Health Promotion Officer), representatives from local voluntary and state sectors in the area, the local RAPID Co-ordinator and - most importantly - interested local people. The role of the Advisory Group was to oversee development of the HAZ initiative locally, from work-plan development through to implementation and evaluation.

Ethnography was, effectively, carried out in a conscious way every day in the community -
in walking through housing estates and open areas, in being a customer in the local shop, Post Office or Pharmacy, in observing the environment, in noting the patterns and schedules of people’s lives.

While Public Health Nurses and other front line HSE staff had a long tradition of domiciliary visits etc. HAZ created opportunities for front line HSE staff to deliver health services in community settings. Here, people could feel comfortable and un-threatened by formal health service settings and buildings (often at least a bus ride away.) They also had the backup of a community Health Worker to further engage with them, informally - for example by encouraging them to join a local walking group or come to a health taster day and so forth.

From a HSE perspective, this began the preparation for community participation in Primary Care Teams, following the publication of the Primary Care Strategy (Primary Care: -A new Direction, 2001) and, in theory, this allowed the HAZ initiative to inform the development of Primary Care Teams. Over a decade on, links are by now well established with Primary Care Teams – though such linking is stronger in some areas than in others. In all areas, however, a monthly schedule of HAZ activities are sent to Primary Care Teams and HSE staff are encouraged to inform service users of such activities in their own area as appropriate.

There have been instances where the local Primary Care Team and/or other HSE services will approach HAZ with a view to addressing chronic illnesses (for example; Type 2 Diabetes, Asthma) or a particular current health issue (an outbreak of a communicable disease) and will together develop a creative approach in response to the need. The HSE utilises the Community Health Worker/Fieldworker as the local expert and the Community Health Worker in turn utilises her/his expertise to formulate a response together with the local community – a response that is collaborative by contrast with the solo efforts of any one agency.

The Community Health Worker, the *dialogic fieldworker*, became the advocate, the organiser, the health champion in the community helping to develop responses to the community’s health needs in creative and never-before-heard-of ways. Paths are negotiated and responses adapted, as required, as the needs and dynamics of the community change.

Outcomes of the Health Action Zone Programme initiatives were recorded in an evaluation exercise prior to the mainstreaming of the Project. Successes were physically visible within communities every day – for instance, people were walking more as walking routes developed, community and individual linkages with local front line HSE staff were visibly enhanced - particularly in the areas of Mental Health, Health Promotion and Public Health Nursing. Each HAZ initiative comprised partnerships which involved symbiotic relationships between local communities and statutory agencies such as those of An Gárda Síochana, the Educational sector, the HSE itself and National organisations such as the Irish Heart Foundation and the Irish Cancer Society. Most recently, significant links have been established with the Cork Healthy Cities Initiative under the aegis of Cork City Council and the HSE.

The fundamental aim of the HAZ programme was to create sustainable health improvements in its area of operation. Community Health Workers strove to identify health champions from within the community, supporting and empowering them along the way to take the lead in the organising and realising of initiatives such as the Walking Groups and the Community Garden among others to be described below. With the Community Health Worker monitoring successes and facilitating fresh responses to emerging needs, the community
itself, to a significant degree, takes possession of and gives effect to central elements of community health and well-being.

Built out of existing resources and on a basis of local knowledge, HAZ Projects were developed – and continue to be operated - in culturally appropriate ways that involve partnership between health care-giving agencies in the community – informal and formal, voluntary and official. Four such projects can be outlined here.

1. The Glen Growing Project

The Glen Growing Project - in an area of 100% local authority housing with no local shop and very limited green space - provides local people with access to a community growing plot (Glen Community Garden). They tend this plot weekly with the help of the local Community Health Worker who provides them with the equipment and raw materials to produce fresh fruit and vegetables, thereby providing opportunities for social networking and a sense of belonging and ownership in addition to education in healthy eating and other physical and mental health benefits.

The project has been highly successful within the local area and has got regional and national recognition for its innovations and successes as a community health initiative.

The group are exploring such additions as a ‘Green Gym’ and a sensory garden for local children as a further development of the project.

The role of the Community Health Worker here, as in all the other HAZ -area projects, incorporates crucial actions such as being a key link person between the community and HSE services. Within the wider community itself, their role - as facilitator, reviewer, evaluator, signposter (as well as participant vegetable gardener!) – is frequently one of building relationships and creating space for interactions – thus furthering the kind and quality of reciprocity that is conceptualised in Kleinman’s idea of care as ‘moral experience’.

2. The Nash’s Boreen Walking Group

Nash’s Boreen, high in the Farranree/Fairhill area of the City is a very old walking and recreation site with rich oral history and superb views over the countryside. Until recently a grossly neglected area subject to widespread dumping and anti-social behavior, it has through community efforts, facilitated by the Health Action Zone Programme and the local authority, benefited from a plan of works – both physical and social - to restore its accessibility. Now, as an official walking route, it is heavily used by the local community in general. According to one resident – “It’s like a Corpus Christi procession on some evenings, such is the activity, with people walking and enjoying the best of the countryside.” (‘Residents Saved Nash’s Boreen’) Walkers’ conversations on these evenings can readily constitute a reciprocal
channel for intergenerational transmission of the Oral Lore of the Northside – to the benefit of Northside social cohesion.

Specifically, a weekly HAZ Walking Group - led at this stage by trained local Walk Leaders - provides opportunities for a wide range of community members to engage in physical activity within a supportive and on occasion, therapeutic environment.

The Community Health Worker in this case, as in other HAZ areas, links with the local Primary Health Care Team – to ensure that the opportunities to engage in other community health activities in their locality, including walking groups, are widely known among users of Primary Health Care services.

Nash’s Boreen today, exemplifies in both physical and dynamic ways the benefits to the community of the reciprocity and care provision that derive from community partnership.

3. National Cancer Screening Programme (‘The Bra Project’)

In response to critically low cancer screening uptake levels (much lower than the national average) in the most disadvantaged areas of Cork’s Northside - HAZ and BreastCheck and a local community group in Knocknaheeny, NICHE - co-operated in the development of a pilot Breast screening programme across the Northside (‘The Bra Project’).

The HAZ Community Health Worker along with a range of partners acted to identify local women and groups to engage with the project – the majority of these women were already involved in HAZ and/or local community groups.

A Peer Education programme involved 50 of these local women, who were trained to provide accurate information on breast and cervical screening to their peers in addition to ‘marketing’ the screening locally. They offered support to people attending Breast Check over a 3 month period during this pilot phase.

Another strand of the programme involved the creation of an art installation known locally as the ‘Bra Project’. A community artist worked with a group of local women to further promote breast health by reducing the embarrassment and discomfort associated with breast screening. By means of a weekly art group, the women developed works of art based on decoration and other creative treatment of personal items of clothing.

The success of this initiative can be judged by the enthusiasm of the initial response by local people to an exhibition of the results of the art group in addition to a 70% uptake rate for first time invitees for Breast Check.

The exhibition tours Cork as a means of sharing the health message in a fun and creative way – even making it to Cork City Hall! It has also been showcased for visitors to the City, including, most recently, a Shanghai delegation interested in the concept of Community Health, and closer to home, high level of HSE management.

The ‘Bra Project’ amounted to the communication of a health message as a creative ‘gift’, embedded within local knowledge and shareable further afield as art. Since this artwork proceeded to public display
and significance from a basis in the intimately personal, the ‘Bra Project’ is, it can be claimed, an instance of community healthcare that is theory-rich in issues of agency, gender and personhood such as are dealt with in the writings of Gell and Strathern.

4. Men’s Health Checks

Mick Moriarty’s Barber shop (‘The Baldy Barber’) in the Blackpool area of the City was the pilot site for the Men’s Health Checks initiative, and where - over one week in 2005 – health checks and haircuts were provided to 70 men.

This is an example of the HAZ project having the local knowledge and relationships that allows the HSE to identify a platform to engage in innovative health related activities within communities. Arising from shared learning with Practitioners from the UK who had engaged in pioneering and innovative work with men - which included, providing health checks at truck stops – HAZ were able to adapt the concept to address the health engagement deficit within this local area of disadvantage (Heart & Lifestyle Health Check).

Over the following 5 years, health checks were held in the credit union, the post office, and the pub – each organised by the local Community Health Worker and operated by a cardiovascular Public Health Nurse. The checks identified those at risk of cardiovascular disease and offered advice on how to reduce this risk - together with referral, where necessary, for further assessment and follow-up by the person’s General Practitioner (GP).

While the health checks were structured, they were not administered mechanically in ‘15 minute slots’. Space and time were created, in places where the men felt comfortable, for meaningful interactions with medical professionals in ways which may have not been readily available to them previously. The project had the added benefit of having the local CHW providing a ‘friendly face’ and a ‘way into’ other health related activities in the community, thus keeping the men in question engaged with their health into the future.

While the initiative corresponded well to aims and objectives within the HSE Primary Care Strategy, the HSE found itself, after a period, no longer able to release staff for the health checks – for example the Cardiovascular Public Health Nurse. Because of this the Men’s Health Check didn’t become embedded into local community life or continue as an element of HSE Operational Plans.

However, there is hope! More recently, in my role as HSE Community Worker in Mallow (30 KMS away and 10 years later) we were able to replicate the initiative in both an Agribusiness Co-op and in a local barber shop. This involved the building of appropriate relationships with my HSE colleagues and the bringing of Health Care out of the Primary Health Care Centre and into the local Co-op store. This could be seen as a reciprocal ‘gifting’ process which responded to a need to engage with the men of the area regarding their health, a need on the part of the Public Health Nurses to promote their Diabetes Programme and the Agribusiness’s desire to increase footfall at the Co-op!
Conclusion

In keeping with the theme of the Conference, unpacking, theorising and reimagining Care and Caregiving - it may, in conclusion, be appropriate to view Community Health Project work of the kind outlined here against an extended theoretical framework drawing on a variety of anthropological concepts.

The Northside areas of chronic disadvantage are a somewhat milder version of the Terrain of Social Exclusion and Social Suffering that Kleinman recognises in what he terms ‘the toxic and predatory environments of urban slums and shantytowns worldwide’ (Kleinman 2012: 118).

In this regard we might consider the relevance of Homi Bhabha’s notion of ‘unhomeliness’ to the marginalised state of dislocated and unsecured individuals and groups of the Northside. For Bhabha (1994) the hybridity and transience of cultural and personal identity in a postmodern world can, in terms of the trauma of daily life, give rise to the condition of ‘unhomliness’. We might well consider that certain categories of people on Cork’s Northside come near to that condition of ‘unhomliness’ in the traumas of their daily lives. Migrants, Refugees, Travellers as well as an underlying stratum of the Settled society of the Northside can be seen to be at risk of ‘unhomliness’ in that as well as experiencing poverty, discrimination, other disadvantage such as disability and disease, they can also experience severe marginalization and exclusion in relation to social status and access to health services. Such individuals and families can be seen as having, in Bhabha’s terms, no place of their own in the ‘system’ and being subject to direction and control by ‘superior’ and bureaucratic authority. Living in a transitional space of clashing cultural differences, a sense of national, local and personal identity can be undermined in the case not only of members of a migrant, refugee and Traveller population but also of ‘local’ individuals and families experiencing high levels of stress and dislocation in the course of ‘ordinary’ life.

In the social suffering among the excluded within areas of chronic disadvantage such as Cork’s Northside (including its Traveller/ethnic minorities) - one can see exemplified what has been called (Massimo 2008) ‘the glaring discrepancy between modernity’s ideal expectations of the social world and the lived experience of its history’. This is the fundamental context to be taken into account in the need for and provision of community healthcare on Cork’s Northside.

In their altruistic, albeit institutionalised, response to this, HAZ Projects might - in theory – see themselves as addressing the promotion of ‘attachment’ - in a psychological sense – (Bowlby 1969, 1990) in order to counteract ‘Unhomeliness’ and the Trauma of dislocation and insecurity. Bowlby’s work in establishing and promoting the concept of Attachment - and its fundamental importance to the well-being of the individual - is generally understood to pertain primarily to the domain of the child. ‘Attachment Theory’ has, of course, been immensely developed by other theorists in the intervening decades and it can be understood as applying equally to
other domains of life in which separation and dislocation render individuals prone to anxiety and other forms of emotional distress related to versions of unhomliness. For Bhabha, the archetypal instance is that of the marginalised ‘migrant’ other, excluded from truly belonging within the ‘system’. Absence or loss of ‘attachment’ - whether in the case of a child separated from a parent by bereavement or otherwise, or in the case of a whole migrant family or an ethnic minority/Traveller family experiencing exclusion from aspects of wider society – constitutes a health need requiring serious intervention/response in terms of community Caregiving. It is obviously the case that psychological resources and expertise are required in such instances to combine with other formal resources and with voluntary agencies in order to address specifically the specific Attachment issues.

HAZ Projects can, in theory, see themselves as essentially having the nature of gift-exchange, whereby the marginalised and the disadvantaged receive inclusionary participation in a Project and, in return, bestow on community life gifts of a verbal, nutritional or artefactual kind. In attempting to promote creative self-expression through a variety of physical and ‘artistic’ activities that can lead to the enhancement of identity, personhood, and social status along lines discussed by Alfred Gell in relation to the mediation of social agency by art objects. (Gell 1998). The Glen Growing Project and ‘The Bra Project’ can readily be understood as engaging with personal forms of artistic and artefactual technological activity on the part of participants to the benefit of their various individual standings in terms of social inclusion, identity and social status. All the Projects have aspects and elements that can be thought of as being congruent with the thinking of Alfred Gell with respect to the nature of art. For Gell, art is a special kind of technology that operates as a device for securing the acquiescence of individuals within the network of intentionalities in which they are enmeshed and, thereby, for motivating responses of esteem, inclusivity and status that counteract the marginalisation of individuals.

Such thinking ties in with and builds on notions of reciprocity deriving from the work of Marcel Mauss (1924) in seeing the object given as bearing the identity of the giver – an identity which the recipient acquires within a transactional field on which persons as well as objects acquire their identities from the relationships in which they transact and are transacted. This relational approach is given its maximum expression in the writings and analysis of Melanesian society by Marilyn Strathern (1988). One commentator ( Carrithers 1996 ), tracing a connection from Mauss through Louis Dumont to Strathern suggests that it would be ‘faithful to the character of Melanesian society to regard people within it not as individuals – that is, as indivisible and autonomous wholes – but as being constituted by properties, goods and substances exchanged or shared with others’. The capacity for reconstruction and reattachment - through participation in HAZ Caregiving Projects - in the case of Northside individuals dislocated and marginalised by virtue of unhomliness type factors can be recognised and encouraged in the light of the analyses of Strathern and Gell.

Alfred Gell had accepted Strathern’s notion of the ‘partible’ or ‘distributed’ person and Chapter Seven of his book (Gell 1998 ) entitled ‘The Distributed Person’ explores ways of envisaging the operation of artistic creativity and the distribution of art and artefacts in society. These ideas in particular can inform in imaginative ways the attempts in HAZ projects to promote personhood, inclusivity and esteem in the face of unhomliness, marginalisation and exclusion.

Attachment-promoting and creativity-promoting dimensions of HAZ Projects can be envisaged as forms of Treatment for the
Trauma of social suffering in the case of the marginalised and disadvantaged on Cork’s Northside. The reimagining of community caregiving activities on the lines suggested here – beginning from the ‘gift’/’moral experience’ nature of the transactions that comprise the Projects - and attempts to draw on such anthropological theorising as has been touched on can usefully contribute further to progressing such Caregiving Treatment.

Since an essential theme of the Conference was the reimagining of Care, invoking such theoretical perspectives as have been mentioned in this paper offers enriching and emancipator prospects for all sides of such altruistic Caregiving enterprises as the Projects of the Northside HAZ Programme.

Finally one can note that the construction of actual Primary Care Centres in the communities of disadvantage where HAZ operates – ‘islands’ about which Project participants ‘journey’ in the course of their various pursuits - can offer the theoretical possibility of regarding the health-enhancing activities and the social relationships that the work promotes as constituting a circularity of Caregiving throughout the territory of the community that is faintly reminiscent of another famous circularity (Malinowski 1922; Uberoi 1962) also involving status-enhancing prestation!

References


Notes
ARTICLE

THE INVOLVEMENT OF MEN IN CARE. MEN’S EXPERIENCES AS FAMILY CAREGIVERS OF DEPENDENT ADULTS*

BY DOLORS COMAS D’ARGEMIR

Abstract: In this paper we present the initial results of an ongoing research project in Catalonia (Spain) on the subject of men’s involvement in caring for dependent adults in the family setting. The results show that changes in the gender system are related to changes in kinship-based obligations. A typology of male carers emerges from the findings based on attitudes to caring: management attitude, responsible attitude, efficient attitude, and exceptional attitude (those who attach value to the exceptional nature of their male carer status). In this paper we analyse the strategies and motivations for caring with an emphasis on the role of gender and kinship.

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Introduction

This paper explores the experiences and perceptions of men who are caring for adult dependents in the family setting. There is clear consensus in the research on caring that women play the most important role. The feminist academic literature has highlighted how women’s social pathways are hindered by their involvement in caring, and how caring is a key component of gender inequalities (Carrasco et al 2011). The question therefore arises of whether men’s involvement in care work alters the sexual division of labour and gender inequalities.

Our understanding is that caring for adults differs from caring for children in both motivation and commitment to care. Caring in childhood is associated with growth and life; it is valued socially and is regarded as an investment in the future. In contrast, the social perception of caring for dependent adults, especially elderly people, is negative because it does not generate value; it is associated with negation and loss and is regarded as an economic and social burden (Federeci 2015). While men may be motivated to care for children by its connotations of modernity and its association with ideals of equality between men and women, caring for adults is a response to the circumstances that demand it. An important challenge today is precisely how to involve men in caring for adults, whether in response to circumstantial needs, or as new agents participating in family and community work.

Although there are still fewer men than women who care for adult dependents, their numbers are not insignificant and will grow in the coming years as a result of social and demographic trends. A survey carried out in Spain in 2004 revealed that 85% of family
carers were women (IMSERSO 2005); although male carers accounted for just 15%, this percentage was higher among older men. Significantly, the percentage of carer husbands (19%) was higher than that of carer wives (12%), and in the case of patients with Alzheimer’s disease the percentage of male carers rose to 41%.

Men’s involvement in care work, paid or unpaid has begun to attract research interest but it is still an open field that requires further systemisation. Men have often been treated as a homogenous group in the literature, and the distinction is not always made between caring for adults and caring for children. Much of the research has centred on masculine identity and how it is negotiated (Calasanti and Bowen 2006, Hanlon 2012, Kirs 2000, Kluczyńska 2015, Ribeiro et al 2007, Thompson 2002), and also on the way men approach their new role as carers (Allen and Webster 2001, Crespo and López 2008, Milligan and Morbey 2013, Milne and Hatzidimitriadou 2003, Robinson et al 2016, Russell 2001). Further exploration is needed into what motivates men to care, and of how care is understood and organised. The age, social differences and nature of the illness of the person receiving the care mean the situations generated are very diverse. Economic and social context and the impact of changes in gender patterns must also be taken into account.

The carer’s situation vis-à-vis the labour market is also essential to any understanding of involvement in family caring. Carmichael and Hulme (2010) note that the likelihood of providing unpaid care in the family setting is higher in cases of individuals outside the labour market or who are in low-paid jobs. This may be one of the reasons why most men caring for dependent adults are either retired or unemployed. Consequently, the economic crisis – which has had a major impact on the labour market – has modified the organisation of social care and the sexual division of labour: cuts in public services and benefits and the refamiliarisation of care have forced some men to take on the caregiving role.

Moral obligation, reciprocity and affection permeate care and reveal the importance of kinship links. But while the academic literature on care has highlighted the importance of gender in the sexual division of labour, in contrast it has neglected the role of kinship, which it takes for granted and naturalises. It is crucial to understand why certain kinship links are activated in caring and how they combine with gender. As Yaganisako and Collier (1987) point out, gender and kinship are interrelated.

This paper is based on a study of male participation in care work we are conducting in Catalonia. The main research method used is open interviews, together with observation and focused discussion groups. The research approach is collaborative, with the participation of both public and private bodies and institutions. Regarding the family carers, we draw from 42 interviews with 20 men of working age and 22 men over the age of 65 (four of whom were over the age of 80). The largest group were husbands (19), followed by fathers (11) and sons (9), but we also came across brothers (3), sons-in-law (1) and grandsons (1).

Men who care: labour market, gender and kinship

Men began to take on the role of caring for adult dependents in Spain in the context of the care crisis and the economic crisis. The crisis of care reflects the difficulties families and society face in attending to the growing needs for care, linked particularly to the “ageing of ageing” (currently 5% of the population is over the age of 80). The situation has worsened with the economic crisis and the ensuing rise in rates of unemployment and poverty. Furthermore,
the state has reduced the services and benefits for long-term care that were provided for in the Spanish Dependency Law (Comas-d’Argemir 2015, Deusdad et al 2016). This has had two related effects. First, caring is re-familiarised, reinforcing the role of women as carers and also driving more men to become involved in care work. Second, people attach much more importance to having a job. Hence, families consider it more important for those in paid work to hold on to their jobs, and for care work to be done by other family members – women or men – who have worse employment prospects or who are outside the labour market.

This twofold circumstance (refamiliarisation of care and the greater value attached to paid work) favours a situation in which gender boundaries are crossed and men take on family care work. In addition, the lack of resources invested in caring reactivates the sense of obligation deriving from kinship links.

Who are these male carers? In this context of economic crisis, falling household resources and unemployment the following profiles of male carers emerge: a) retired men who care for their wives or other family members; b) unemployed men who look after their parents, their children or their wives; c) men who are carers because there are no women in the family; and d) exceptional men who take responsibility for care tasks themselves or share them with others. The first two profiles correspond to men who are outside the labour market, while the last two may balance caring tasks with paid employment.

Retired men caring for their wives do not consider their masculine identity to be affected by this role despite having been socialised in the patterns of hegemonic masculinity. Indeed, at this point in their lives when they have more time, caring gives them a new sense of their position in society now they are no longer defined by their job. Statements such as “I’m a man but I’m a carer” reflect how role segregation is present in their lives, but also their acceptance of their new responsibilities. The feeling of family duty is reflected in their dedication to caring; similarly, reciprocity is shown in the way they give back the care they have received.

Working age men who are unemployed care for a family member when they are the only ones in the family setting who have the time to do so. They view this situation as unsatisfactory and circumstantial, and in the hypothetical case of their finding a job the situation would ideally return to normal. Nonetheless, the younger men’s discourse does not express the rigid segregation of roles typical of their older counterparts; rather they accept caring as a normalised option, although not an option they would choose. And although they insist that “it’s normal for men to care”, their unease at not having a job is apparent.

The men who care because there are no women in the family (only sons, for example, or men with no sisters or daughters) take on the role of carer as part of their family obligations, and if they are in paid work they try to balance their family and work responsibilities by mobilising resources to provide the care.

Finally, there are some men who become involved in caring as an option in itself because they feel drawn by the situation of the person in need of care. It is an option that reflects changes in gender patterns. Some sons take on the care of their elderly parents, for example, either because they wish to do so, or because they cannot delegate responsibility for caring to their wives or other relatives. This type of involvement can be compatible with other help or support, and may be shared among various people. These are emerging models of egalitarian men who are still the exception today and who reflect the changes in gender patterns.

Men care for others when there are no women to do so and there are few exceptions
to this rule. It might therefore be said that this situation complies with gender patterns, but this is not the case. In the situations we have analysed women are not necessarily absent in the family, but rather they cannot take on caring tasks or they do not feel involved. Some of the reasons that limit women’s capacity to care (whether they be daughters, sisters or wives) are that they are in paid work, they have moved away or emigrated and no longer live in the area, or because as well as their paid work they have their own family responsibilities. In addition, some women do not feel obliged to care for their husband’s parents.

These situations also reflect other important changes that have altered the conditions of care in families: changes in women’s lives stemming from their higher levels of education and their presence in the labour market, changes in the family, the fragmentation of urban life, the disintegration and reduction of support networks. They also reflect the value of personal autonomy for older people, who insist that they do not want to depend on their children or relatives. Public policies attending to long-term care have, for their part, had little impact in Spain, which has increased the pressure on families and fostered the use of poorly paid migrant labour. And finally it also reflects the circumstances of the economic crisis.

In a context in which social changes, the crisis of care and the economic crisis are compounded, the protective role of kinship is reactivated and gender roles take second place. This was not the case a few years ago. For example, in the filial relationship it was the daughters, not the sons who did the caring; daughters-in-law, not sons-in-law, looked after parents-in-law. It is significant that in the 2004 survey of carers (IMSERSO 2005) the number of daughters-in-law caring for their parents-in-law (8.6%) was higher than the number of sons caring for their own parents (7.6%). In questions of caring, being a woman prevailed above and beyond any kinship link. We do not have any current data but the interviews revealed that today it is the kinship link that generates the main relationship of obligation.

**Attitudes to caring**

Whether men are caring as an obligation or by choice determines the differences in their attitudes to caring. Unlike women, caring is not part of their masculine role and as men, it transforms them, although this does not call their masculinity into question since it reinforces their protector role. In any case, having to care is experienced in very diverse ways. Retired older husbands gain self esteem and a new meaning to this stage in their lives from the caring role, showing their commitment to and reciprocal relationship with their wives. Because they are performing a non-normative role, their contribution is highly valued by their immediate environment (Milne and Hatzidimitriadou 2003). Unemployed male carers have a different attitude because they are not caring out of choice but because they do not have paid employment and they regard their situation as somewhat provisional.

The motivations to care condition the way men approach care tasks and attend to the needs of the person receiving the care. To differentiate attitudes to care, the practical dimensions must be distinguished from the emotional dimensions of care. The results of our study suggest a typology of male carers according to attitudes, which range from the least to the most involvement. The categories in this typology are not fixed since attitudes and involvement may change in line with the evolving situation of dependence of the person receiving care, or depending on changes in the man’s own employment situation and his ability to devote more or less time to caregiving.
A) Management attitude (those who organise care but do not do it all directly). The defining factor in this attitude is control. The male carer knows all the needs of the person requiring care and finds the resources to meet them. He is involved in the emotional aspects and avoids carrying out instrumental and personal tasks under the assumption that he is not qualified to do so or cannot due to lack of time. To deal with these aspects he looks for support among the extensive family and makes intensive use of available public or private services. This attitude is widespread and is most commonly found among men who have to combine caregiving with their work.

B) Responsible attitude (those who take on care as their responsibility). The defining factor in this attitude is the predominance of the emotional dimension. These men feel morally obliged to care and consider that their knowledge of the person and their affection make them the most satisfactory caregiver. They are involved in the practical day-to-day activities and personal care, tasks that they gradually learn over time and which are sometimes difficult to reconcile with the emotional dimensions. These men also look for complimentary resources in their support and services networks to solve practical issues and leave more space for emotional aspects.

C) Efficient attitude (those who find ways of acquiring specific care skills). The defining factor of this attitude is operative capability. In order to be as efficient as possible in caregiving, these men seek to enhance their capabilities by learning from the experiences of people in their support network and sometimes by taking specific courses. They thereby aim to control the operational dimensions and make them compatible with the emotional aspects, also seeking out public or private resources to facilitate the process. This attitude is frequent in advanced stages of dependence of the person receiving care and when care needs increase.

D) Exceptional attitude (those who attach value to the exceptional nature of their male carer status). This is the attitude of someone who is aware that they are a male carer and of the exceptionality of their role, and who attaches personal and social value to caring. These men achieve maximum efficiency in carrying out practical care tasks by putting emotional dimensions first. They accept help from support networks, public assistance and occasional services, but try to attend to the care tasks themselves. They participate in public and private initiatives designed for carers (training for carers or mutual support groups), which help raise their awareness as male carers.

Our findings show that the action of caring does not necessarily correspond with awareness of being male carers; indeed, we only clearly identify this awareness in the men we define as having an exceptional attitude because as men, they themselves consider this attitude exceptional. The participants in the study understood the concept of “carer” to be a professional person who does care work for money. Attending to the needs of a dependent relative – in sum, caring – is something they consider to be inherent to kinship obligations, whether conjugal or by
filiation. “I’m not a carer; I’m her husband” is a phrase we frequently heard. It reflects the naturalisation of domestic and care tasks, linked to the constructions of gender and kinship. The need to attend to situations of dependency reverses the gender roles when it is the man who has to do the caring, but it continues to perpetuate the naturalisation of care. The fact that caregiving takes place in the family setting and is steeped in moral obligation and affection contributes to its naturalisation and its social invisibility (Comas d’Argemir, 1995).

Male carers cross gender boundaries, performing activities previously done by the person receiving the care that are new to them and have to be learned. These boundaries are also crossed when they try to put themselves in the situation of the person receiving care; they recognise the gendered dimension of the person they are caring for and try to meet their needs not only as a person, but also specifically as a woman or as a man. Husband carers try to act in line with their wives’ tastes; they take pains to dress them, do their hair and so on with great respect for their female status. Hence when men care for women, not only do they have to learn how to do domestic and caring tasks, but they also have to do them within the frame of a gender identity that is not their own (Calasanti and Bowen, 2006).

Domestic and caring tasks may be carried out fully by the men themselves, but help may also come in the form of hired helpers, public and private resources and support from other members of the family. The capability to mobilise resources and obtain help depends on the male carers’ economic capacity and their social and cultural capital.

The perception that care provided within the family is the best option for the person receiving care is not inconsistent with the acceptance of and demand for services and benefits from public authorities. Our study uncovered grievances and anger about insufficient public support and the participants consider that there should be greater public involvement in caring. The expectations generated when the Dependency Law came onto the statute books in 2006 have been frustrated by public spending cuts, the withdrawal of some benefits, reduction of services and the long waiting periods to access those remaining services.

While male carers explicitly asserted their need to receive public support and highlighted their own work and efforts, they played down the importance of the help they receive from their support network and from people employed to do domestic and care tasks. In their accounts, their descriptions of the “help” they receive are fragmented, diluted among the explanations of the tasks they carry out themselves. But in their accounts the following people gradually emerge: women employed to clean the house; family workers; daughters who wash and iron the clothes; who invite their parents for lunch on Sundays; who take care of personal hygiene tasks; who oversee medication; or who accompany their parents to doctors’ appointments. A network of resources, often provided by the extended family but also by institutions, organisations or the market, is activated around the husband carer, especially in the case of retired husbands; this network of resources should be taken into account in any attempt to understand the care strategy in the family setting. When male carers are in active employment, these resources are used more intensively and they seek out other means of support such as day centres, lunch groups, old people’s homes, people employed to provide care in the home, and so on.

Conclusions

In this paper we have analysed the experiences and perceptions of men caring for dependent adults in the context of a dual
crisis: the economic crisis and the care crisis. We have shown that the refamiliarisation of caring and the increased value accorded to employment favours the incorporation of men into family care roles.

Men who care for other adults in the family setting are mainly outside the labour market: retired men, unemployed men and others who have left poorly paid jobs. Their situation vis-à-vis the labour market is essential to our understanding of men’s and women’s involvement in caregiving, and in times of crisis men take on the caring role when women cannot do so, especially if the women are working and in better paid jobs.

Men who care are not a homogenous group. The results of our research suggest a typology of male carers according to their attitudes: management attitude (those who organise care but do not do it all directly), responsible attitude (those who take on care as their responsibility); efficient attitude (those who find ways of acquiring specific care skills), and exceptional attitude (those who attach value to the exceptional nature of their male carer status). We have also shown that economic capacity and social and cultural capital have an impact on their ability to mobilise resources and support.

In all these cases we have seen the resignification of gender and kinship. Male carers cross gender boundaries; they undertake activities that are new to them and that they have to learn. In addition, the lack of resources for caring reactivates and modifies the sense of duty deriving from kinship links, strengthening the duty of the conjugal or parental link over the obligations of sons and daughters or other family members.

These changes in the role of gender and kinship in care show that the relational and contextual dimensions matter, and not only the substance of the links. It is not enough to be kin; one has to “do kinship”, and men who care have incorporated new obligations into their kinship roles. The same may be said with regard to gender: being a man does not prevent one from caring, thus altering the very content of gender roles. Social and cultural conditions oblige certain links to mobilise and reshape the forms of self-attention based on moral obligations, reciprocity, mutuality and affection, which are not without their tensions, contradictions and conflicts.

At the beginning of this paper we asked whether men’s incorporation into caregiving ties in with gender equality. Emerging models of masculinity would suggest that it does, since these are egalitarian men who take on a new role as carers traditionally associated with women. Most male carers, however, do so when women are not able to and this in itself reproduces gender patterns and male hegemony. But what our research reveals is that men can care, despite not having been socialised to do so, and that motivation or need overcome their lack of initial knowledge or skills. Once again, it must be asserted that the capacity to care is not natural but cultural, and that men can care just as much as women.

References


Article

Redefining the Body: Culture and Politics within Globalized Debates on Customary Female Genital Cutting Practices

By Máire Ní Mhórdha

Abstract: This paper offers a critical analysis of contemporary debates on customary African female genital cutting (FGC) practices. Largely framed within an understanding of FGC (also referred to as female circumcision, or female genital mutilation) as a violation of the right to bodily integrity, as well as the right to health, these debates are often infused with a rhetoric of caring and concern for the well-being of the African women and girls who undergo these rituals. This paper unpacks these debates, drawing on long-term ethnographic fieldwork in Senegal with an international non-governmental organisation (NGO) working to combat FGC, highlighting the ways in which projects such as these are culturally, politically and ideologically rooted in particular beliefs about health and sexuality, and reflective of contemporary politics about external intervention in the lives of people in Africa.

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Introduction

The ethnographic subject of this paper is an American NGO based in Senegal, called Tostan, which works to bring about the abandonment of FGC practices through a human rights education programme. The analytical approach taken here locates and frames this NGO’s official position and activities within a wider epistemological and ideological movement that defines and reifies FGC as a ‘harmful traditional practice’ via self-referential debates of a largely ethnocentric nature.

I draw on three years of multi-sited ethnographic fieldwork, in Dakar at the NGO’s headquarters and in rural Casamance in a predominantly Jola Fonyi village which had undergone Tostan’s programme and had theoretically abandoned female genital cutting, which was practised there as the first stage in a two-part coming-of-age ritual for girls called the ŋakay.

Tostan’s village education programme, called the ‘Community Empowerment Program,’ is founded on the idea of the transmission of ‘good information’ (Tostan 2011), in particular international human rights doctrine, to its largely rural programme beneficiaries, operating on the assumption that once participants have knowledge of human rights, they will come to view practices such as FGC as a rights violation that must logically be abandoned.
Tostan’s information transfer approach in local languages using a human rights framework is now considered a best practice model by international institutions such as UNICEF for the elimination of FGC practices in Africa, as it promises ‘abandonment within a generation’ (UNICEF 2007) via ‘non-judgemental, inclusive dialogue’ (Tostan 2014). Senegal, the home of Tostan’s intervention, is thus ‘on the verge of immense social change’ according to its CEO and founder, Molly Melching, in an article penned by her in 2012 in the Huffington Post entitled ‘The Time is Now, the Place is Senegal’ (Melching 2012). The change Melching predicts is the abandonment in Senegal in the near future of ‘the harmful practice of female genital cutting’ by the approximately one quarter of the population that practises it, as a result of Tostan’s ‘transformative education programme’ (ibid.).

FGC in global context

A vast literature, both academic and applied, exists on FGC and within which Tostan’s approach now features strongly (e.g. Hernlund and Shell-Duncan 2007; Johnson 2003). Across this literature, the female body is frequently the site of ideological conflict. Discourses surrounding the practices have historically ranged from the ‘horrified responses’ of colonial missionaries and the ‘outraged sensibilities’ of Western feminists and activists, to ‘providing anti-colonialists with fuel for nationalist struggles’ (James 1998: 1033). FGC has become a topic of ever-increasing popular and political interest, especially in the West.

FGC practices initially came under the global political spotlight in the 1970s, although they had been raised for debate many decades prior in a number of countries including Kenya and Sudan, placing them ‘on the front line of a “culture” war between “traditionalists” and “modernists.”’ Since then, a plethora of literature has been produced, and interventions of various kinds carried out globally, sparked by the 1978 publication of US feminist Mary Daly’s Gyn/Ecology: the Metaethics of Radical Feminism, followed by Fran Hosken’s Hosken Report (1979). These works referred to the practices as the ‘mutilation,’ ‘torture’ and ‘sexual castration’ of women. The extreme language of these and other representations, in tandem with more sanitized ‘scientific’ descriptions such as ‘infibulation’ and ‘clitoridectomy,’ have served to fuel a judgment of unequivocal condemnation in the West that persists to the present day.

Sociologist Elizabeth Heger Boyle (2002: 42) argues that the emerging feminist critiques that brought FGC to attention internationally were situated within the context of a ‘constant expansion of individual rights and claims’ serving to illustrate ‘individual rights discourse conquering first national autonomy and then family inviolability.’ Many of these feminist accounts situated the issue among discourses of power, individualism and self-interest (e.g. Daly 1978). Boyle argues that, on a subtle level, the assumption underpinning these discourses is that actions motivated by factors other than self-interest (such as religious or familial obligations) are in some way illegitimate, and that, with the ever-expanding notion of rights, rationalism and individualism will ‘win out’ over previous institutional and social structures (Boyle 2002).

A cohort of ‘concerned research scholars, physicians, and policy experts’ (that includes Sierra Leonean-American anthropologist Fuambai Ahmadu, who chose as an adult to undergo FGC in Sierra Leone as part of the Kono initiation rite), recently argued that ‘media coverage of female genital modifications in Africa has been hyperbolic and one-sided, presenting them uniformly as
mutilation and ignoring the cultural complexities that underlie these practices’ (Abdulcadir et al. 2012: 19). Most media commentary in Europe and the United States (Tostan’s donor regions) draw on sources from within the global activist and advocacy movement, with few alternative voices being reported, as women who have undergone ‘FGM’ are portrayed as ‘victims’ or ‘survivors’ in articles with emotive titles such as ‘I Was Robbed of My Life’ (Trust.org 2012). By identifying the African woman as either silent victim or global womanist, thereby ‘feeding into Western feminist accounts of oppressed “third world” women’ (Kea and Roberts-Holmes 2012: 96), these narratives constitute Western subjectivities: ‘like footbinding, plural marriage, and veiling, FGCs have been framed for Western audiences as both women’s oppression and cultural depravity, potentially inspiring both feminist and exemplarist sentiment’ (Wade 2009: 296).

Human rights and the politics of global debates on FGC
By the 1990s, condemnations of FGC on the basis of health risks were increasingly replaced with arguments founded on the doctrine of universal human rights (Shell-Duncan and Hernlund 2000: 25). Indeed, Tostan specifically states in its training manual that FGC violates the following rights: the right to health; the right to physical integrity; the right to be protected from all forms of violence; the right to be protected from all forms of discrimination. In this regard, global debates on FGC have now become in a sense ‘non-debates,’ I suggest, as the dominant consensus has become that female genital alteration practices in Africa of any type (whether performed on children or adults) are harmful and must be halted, with the ‘debate’ largely centring on questions of how and why this should happen. Indeed, the perceived ills of the practices and their eradication have now become a cause célèbre among global political elites. Henrietta Moore (2007: 327) contends that, ‘female genital operations raise with particular force the question of the nature of politics in a globalized world,’ an observation exemplified by the endorsement of Tostan by powerful political actors such as former US First Lady

Health and sexuality within debates on FGC
Bordering These globalized debates incorporate concepts of the body, self, sexuality, family and morality, and play upon tensions related to cultural difference and the legacy of colonial-era depictions of gender relations in Africa. Attention is now largely focused within FGC discourses on their presumed damaging impacts on women’s health and sexual enjoyment. Whereas early outside intervention into the practices in Africa tended to focus on health (Pederson 1991), Western feminism and science’s turn to the clitoris as a site of female sexual pleasure, signifying the unencumbered individual in relation to the world (Harvey 2002; Laqueur 1990), influenced the shift in emphasis within anti-FGC campaigns from impacts on health, to sexual fulfilment. However, due to a lack of reliable, long-term data on both of these indicators—with ethnographic research by Obermeyer (1999; 2003), Abusharaf (2001) and Lightfoot-Klein (1989) belying claims of inevitable damage to health and sexuality—as Duncan Wax argues, ‘FGC has proven an empty template for the projection of Western conceptions of sex and sexuality and their relation to individual identity’ (Wax 2006). Kirsten Bell criticizes the tendency ‘to homogenize female genital surgeries and to equate operations diverse in form and function with their most severe manifestations, while simultaneously reducing their meaning to patriarchy’ (Bell 2005: 125). Johnsdotter and Essen (2013: 3) note the ‘political impetus to exaggerate negative effects on sexuality’ in the absence of rigorous research in support of such claims.
and, Secretary of State, and current Presidential candidate, Hillary Clinton. Clinton’s ‘Remarks at the International Day of Zero Tolerance for Female Genital Mutilation’ at the U.S. State Department in 2012 included discussion of her experience in Senegal with Tostan, and introduced Tostan founder Melching as, ‘a real hero of mine, a friend of mine’ (U.S. Department of State 2012). During this speech, Hillary Clinton warned:

Now we cannot excuse this as a cultural tradition. There are many cultural traditions that used to exist in many parts of the world that are no longer acceptable. We cannot excuse it as a private matter because it has very broad public implications. It has no medical benefits. It is, plain and simple, a human rights violation (ibid.)

The employment of the language of human rights here indicates a belief in the universal existence and applicability of these rights across time and space, a belief increasingly appropriated by the powerful to ensure the erasure of all contrary expressions as ‘excuses.’ In Clinton’s speech, FGC practices are homogenized as a single anachronistic ‘cultural tradition’ of no value, as ‘it’ is considered to be without any ‘medical benefit’; ‘it’ is ‘no longer acceptable’ in the presumably enlightened era of the present. In this speech, Clinton goes on to remark on ‘the trauma FGC causes’ and highlights how it has become a key issue for US foreign policy, which she claims now aims to enhance the role of women, presumed to be globally oppressed: ‘So we’re elevating this issue, but it’s part of our overall elevation of the role of women and girls in our foreign policy economically, strategically, politically. Every aspect of our policy is intending to highlight and promote the role of women’ (ibid.). She explicitly links the issue to what she views as ‘the deeply-rooted gender inequalities that, either tacitly or actively, permit and promote such practices’ and concludes by expressing the hope that, ‘we can certainly see the abolition of this practice even sooner than within a generation’ (ibid.). Clinton’s speech on this occasion followed on from her remarks at the 1995 United Nations Fourth World Conference on Women in Beijing, when she stated that, ‘it is a violation of human rights when young girls are brutalized by the painful and degrading practice of female genital mutilation’ (United Nations 1995).

The political power of these global discourses is illustrated in the fact that FGC was outlawed in Senegal in 1999 following the high profile visit of President Bill Clinton and First Lady Hillary Clinton to Tostan (a visit cited by Mrs Clinton in her 2012 remarks). Consideration of the context in the United States at the time shows that, in 1996, a Togolese woman named Fauziya Kassindja became the first person to be awarded asylum for ‘gender-based oppression,’ while in the same year the United States passed a federal law against ‘female genital mutilation’ and began imposing economic sanctions on nations that did not attempt to eliminate the practices among their citizens (Boyle 2002); one can assume that the Senegalese politicians passing the law were not unaware of this policy. ‘FGM’ was thus used by US leaders as a ‘convenient marker with which to place a culture on one side of the dichotomy between the modern and the traditional’ (Wade 2009: 296) and yet another excuse for the United States to flex its economic muscle in order to influence policies abroad.

Genital cutting in global discourse: a cultural double standard?

The narrowness of debates on FGC is further exemplified by the outcry surrounding a policy statement made by the American Academy of Pediatrics (AAP) in 2010 suggesting that doctors be permitted to substitute a request by parents for FGC with an uninvasive clitoral ‘nicking’ procedure (MacReady 2010). Despite framing this
suggestion within an overall condemnation of ‘female genital cutting’ and putting it forward as an alternative to more invasive forms of cutting, the AAP subsequently rescinded the statement following intense lobbying led by activist groups such as the New York-based Equality Now, that claimed that the AAP was ‘promoting female genital mutilation’ (Equality Now 2010). Tostan’s CEO explained to me in a 2011 interview that she was equally opposed to the idea of ‘nicking’ as she thought that, ‘it’s terrible, I think people should just stop.’ Melching stated that while visiting Somaliland she was told by a gynaecologist that although people claimed they were performing sunnah (in this case a procedure thought to entail clitoral nicking), they were instead practising infibulation (excision of all or part of the external genitalia and stitching/narrowing of the vaginal opening). She therefore believed that advocating ‘nicking’ was ‘very bad’ as it offered a disguise for other, more invasive forms of cutting. Understandings such as these of all forms of customary (African) FGC practices as both regressive and oppressive, act as diagnostics of discourse in the Foucauldian sense, as powerful conceptual apparatuses which produce knowledge ‘by shap[ing] the thoughts and behaviour of participants by defining the world of permissible assertions (the regime of truth) within which they live and meaningfully interact’ (Boddy 2007: 53). Through these discourses, globalized power relations, while seemingly subverted, are firmly maintained. While feminist activists may invoke notions of global sisterhood and equality, they simultaneously normalize ideas of non-Western people and societies as ‘backward’ and ‘barbaric,’ in need of guidance and rescue.

To illustrate, practices such as labiaplasty (an increasingly popular cosmetic procedure among Euro-American women to alter their genitals, that involves cutting) do not fall under the WHO’s definition of ‘mutilation,’ i.e. ‘injury to the female genital organs for non-medical reasons’ (WHO 2013), indicating a possible double standard, or at least myopia in this global concern for the well-being and intactness of the female genitalia (see Pedwell 2007; Johnsdotter and Essen 2010).

Furthermore, the WHO—and NGOs such as Tostan—does not consider male circumcision, or the genital surgeries performed on newborn babies deemed ‘intersex’ (when gender is ‘assigned’ by physicians at birth, see Shweder et al. 2009) to fall under the category of genital mutilation, even though these also involve the ‘partial or total removal of the external […] genitalia, or other injury to the […] genital organs for non-medical reasons’ (WHO 2013) – the word ‘female’ has been omitted from this quotation from the WHO for illustrative purposes. These types of cutting are also usually performed on minors, without their consent, a major difference being that in the West (especially in the United States) both ‘intersex’ surgery and male circumcision are considered to be scientifically valid, or even medically necessary procedures.

Indeed, parallel with the push to halt FGC in Africa is a massive campaign to promote male circumcision across the continent (primarily funded by the Bill & Melinda Gates Foundation), citing health benefits in relation to HIV transmission from women to men (Aizenman 2014; Gates Foundation 2009). As summarized by Darby and Svoboda, ‘we now find the WHO conducting two quite separate research projects: one to find evidence for the harm of [female circumcision], another to find evidence for the benefits of [male circumcision]’ (Darby and Svoboda 2007: 312).

In fact ‘circumcision’ of females was itself known in the West until relatively recently, and its history highlights how shifts in cultural attitudes (as opposed to scientific opinion) may lead to the preservation or discontinuation of medical practices (Bell
2005). Clitoridectomies were, for example, occasionally advocated in Europe and the United States until the 1960s as a ‘harmless operative procedure’ to ‘cure’ masturbation among females (Sheehan 1981). As Androus (2004: 5) contends, ‘the gendered construction of this issue is based on ethnocentric assumptions about the difference between the genital cutting of boys and of girls.’ Bell argues that the fact that routine male circumcision was taken up as standard in the United States while FGC was never normalized, is explained by understanding the attitudes toward female and male sexuality that developed in this context over the period, arguing that these attitudes are related to Western constructions of male and female sexuality, wherein the latter is assumed to be ‘fragile’ and ‘passive’: ‘woman’s sexual instincts, being fundamentally more delicate, will be crippled by any form of genital surgery’ (Bell 2005: 136, emphasis in original), compared to an ‘instinctive, active’ male sexuality (ibid.: 138).

In a similar vein, Susan Bordo contends that within hegemonic Western discourse, when it comes to sex, ‘mostly, men’s bodies are presented like action-hero toys—wind them up and watch them perform’ (1999, cited in Bell 2005: 138). As J.A. Boon observes, ‘foreskins are facts—cultural facts’ (Boon 1999: 5). Whereas African FGC practices are perceived in the West as a single homogenous ‘cultural’ practice, and ‘a symbol par excellence of patriarchal oppression’ in African societies (Bell 2005: 135), male genital cutting (MGC) procedures that remove the foreskin of non-consenting babies or children (routine neonatal circumcision being most common in the United States, for example), are not considered similarly oppressive or in violation of human rights. As Androus (2009: 37) argues, ‘gender-based differential treatment is untenable if the issue is treated as one of human rights.’ This ‘desire to ignore’ (Tuana 2006: 10) the fact that the same ethical dilemmas may apply to practices such as MGC (blind to the similarity of arguments related to hygiene, aesthetics, religion and tradition invoked in support of MGC to those invoked by many practitioners of FGC) reveals the conceptual distance between male and female genital cutting practices inherent to these narratives and the contradictions characterizing public policies related to them. In this regard, there is no impetus within Tostan to promote abandonment of the circumcision of male infants or children in the interests of human rights (by far the most prevalent form of genital cutting worldwide, and a standard procedure in Senegal, not only as a Muslim prescription, but as a longstanding cultural norm, see Caldwell et al. 1997); just as there is no such impetus within the institutions that fund and support it (e.g. UNICEF or USAID), dominated as they are by Euro-American cultural and political interests.

Interestingly, Tostan’s facilitator training manual for its module on health and hygiene, which describes the male and female genitalia for the education of programme participants itself excises all reference to the male foreskin, which does not feature in either the text or image of the male genitals. Given the dominant political orthodoxy described above championing women’s rights and bodily integrity, consideration of the likely reaction to such an omission applied to any elements of the female genitalia exemplifies the contradiction inherent within contemporary discourses on genital cutting practices. Such global debates on FGC reduce women’s sexuality to the body and so-called biological ‘facts’ about what constitutes a ‘normal’ body (and consequently ‘normal’ sexuality). By focusing on the physical form of female genitalia, ‘normal’ sexuality becomes treated as that given by the body, rather than a product of processes of embodiment, history, culture and context. In this schema, the ‘normal’ body (be it female or male) is itself a product of scientific ‘truths.’ In the process,
the line between ‘normal’ and ‘abnormal’ is produced as ‘truth’ and naturalized, which happens (at least partly), through the production of scientific ‘facts.’ With regard to FGC and ‘normal’ sexuality, Johnsdotter and Essen (2013: 5-6) criticize ‘studies that build upon faulty theoretical assumptions about the role of genitalia in sexuality’:

Possibly, Western researchers in this field are captivated by typically Western constructions of sexuality, which tend to overemphasize the role of anatomy and physiology in framing and describing sexual activities. In the words of Australian sociologist Juliet Richters: ‘as if having sex were a physiological process like digestion rather than a social interaction like having dinner.’

Conclusion

In contrast to organisational narratives that emphasize its ‘movement to abandon FGC’ (Tostan 2013) as a locally-inspired campaign, the ideology of the NGO Tostan is firmly embedded within, and at least partially derived from, the Western-influenced political and cultural framework discussed in this paper. Tostan’s objectives harmonize with Western feminism-inspired discourses and policies that condemn as harmful all forms of customary genital cutting in Africa when conducted on females. As such, opposing the customary genital cutting of women and girls is no longer a radical position for an international NGO to take, and in fact any consideration of an approach other than total abandonment is now unacceptable at the global level, as is evident from the AAP controversy. As Lauren Leve (2001) highlights, focus on women and girls in development is now a dogma (even given the paradoxes that may arise from this focus, see Kea 2007), and NGOs such as Tostan, that seek funding from international and bilateral donors, do not fail to take account of this.

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CARING AGENTS: HOW SLOVAK JOB AGENCIES SELL CARE WORK ABROAD

BY EVA-MARIA WALther

Abstract: Hiring women from Central Eastern Europe as live-in care workers for aging family members has become a widely established solution in Western Europe. The number and importance of transnational job agencies that match potential care workers and families is growing. Previous research on the migration of care workers has so far widely neglected these agencies. Building upon participant observation in two Slovak job agencies implementing care workers into Austrian families, my paper contributes to filling this gap by showing how they create an ideal for care work and promote it by means of their recruitment and training routines for new care workers.

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Introduction

The influx of geriatric care workers from Eastern and Central Europe to Western Europe, especially Germany, Austria, Switzerland and Italy, is a wide-spread and well established phenomenon. The workers, mostly women, stay in the old person’s home around the clock, usually to be rotating with a colleague in a routine of 2 weeks up to 3 months (Morokvasic 2004). In Slovakia, Austria is the most common destination for women who chose this career. Over time, a highly organized market has emerged around the regulation and administration of the care workers’ movement, including professional schools, transport firms and, most notably, job agencies which select Slovak care workers and match them with Austrian families according to their demands and needs. The present paper deals with these agencies’ impact on their care workers’ professional trajectories. Their job is to carefully foster an ideal for care work along the lines of customers’ preconceptions and care workers’ assets, and promote and teach that model with the means they have at hand. My aim is to show to which imperatives agencies need to adapt, and how they motivate and spread their ideal to their caring co-workers.

The migratory wave that is sustained by growing demand for cheap care labour force in Western countries has sparked the interest of social scientists and has led to a considerable number of studies, most of which deal with the migrating women, their motivations for their migratory projects and their personal and professional lives in the hosting countries. These studies unpack the precarious character this work arrangement often entails and depict women’s struggle with isolation and exhaustion. The private
home as a work space is insufficiently regulated and barely controlled, and so care workers are often expected to be constantly available and are denied a sufficient amount of free time and days off (Schillinger 2013, Schwiter/Berndt/ Truong 2015, Simonazzi 2009). On the other hand, care work jobs are easily accessible and require only a low level of formal education, making it a viable option for women of low social status, escaping long time unemployment or re-entering the job market after a longer period of child-rearing. Others use their stay abroad as a stepping stone for other kinds of employment in their countries of destination or origin (Karakayali 2010).

Transnational job agencies take centre stage in this work arrangement. Without agencies, the market could barely be operative:

Agents are especially necessary in the domestic elderly care sector due to the precarious nature of the employer-employee relationship. This precariousness is due in part to the intimate nature of the work: a lack of a good personal relationship between migrant caregiver and patient can lead the migrant to leave the job suddenly. It is also due to the fact that the person being cared for may die unexpectedly or need to be transferred to a hospital or nursing home, which can result in the sudden termination of employment. In either case, it is often necessary to be able to find new employment opportunities at short notice. (Elrick/Lewandowska 2008:723)

Another factor which makes many care workers rely on agency help is the complicated, ever-changing administrative process that precedes border-crossing and employment abroad and which many find difficult to overlook. Agencies are experts in the required documentation and have elaborated intricate audit routines to avoid legal pitfalls (see Lindquist 2015). But despite their importance, transnational job agencies have only been treated in passing by most scholars; some have noted a certain passivity when it comes to addressing problems in the hosting countries or solving conflicts with the families of the clients (Búriková/Miller 2010).

By putting agencies in the spotlight, I follow the call of Johan Lindquist, Biao Xiang and Brenda Yeoh (2012) to ‘Open the Black Box of Migration’: To focus more on what happens between an individual’s choice to migrate and his or her arrival in the receiving country, and thus on the infrastructure of mobility and the actors who organize the necessary intermediate steps. This perspective is crucial for gaining a better understanding of how care services are being sold abroad. In the movement of care workers from the European East to the west, agencies function as doorkeepers: they have a notable impact on who gets to work as a care worker in the first place. They also provide training and advice for the care workers they cooperate with, promoting a certain ideal image of the care worker and care taking as a professional and commercial activity. This paper focuses on the process of recruitment through agencies, thereby showing how they design a module for care work which is both sensitive to clients’ expectations, and to the care workers’ professional success and satisfaction. I did fieldwork for two months in two different recruitment agencies in Slovakia, observing and participating in their daily work routine, and carrying out semi-structured interviews with the employees and the managers. Among the data that inform this paper are the findings from the interviews and from informal conversation with employees and visiting care workers, but also documents issued by the agency, such as handouts with codes of conduct for the care worker and the customer. I think that the ideal notion for care work surfaces most clearly in the agencies’ routines of selecting and instructing new care workers. This is why I will provide an in-depth analysis of an exemplary recruitment and training day I
participated in in one of the agencies. I will start by setting the scene with a short description of the social and legal framework for agencies' business.

**Slovak care-work migration and Austrian legislation**

According to the Wirtschaftskammern Österreich (Austria’s Chambers of Commerce), 56,095 freelancing “Personenbetreuer” (care workers) had a registered business in Austria in December 2015. More than half of them (31,276) are women from Slovakia, followed by Romania and Bulgaria. This alternative to institutional care is not only more desirable for old people, it is also considerably cheaper, not least because the Austrian government supports persons in need of care with an attendance allowance and even a monthly grant for those who decide to take in a live-in care worker. Research on agencies’ websites show that offers for 24-hour care start at around 1000 €, but with the state support, the monthly costs can be reduced to as little as 550 €. The salary of a care worker in Austria ranges between 700 and 2000 € per month, which is considerably more than the Slovak minimum wage of 405 €. However, it must be noted that fees and taxes as well as the agency fees are subtracted from this. The Slovak state promotes care work abroad as a solution to (female) unemployment by offering unemployed women free care work courses. In response to the growing demand, a multitude of care work agencies have sprung up in the past 10 years. Competition on the market is considerable, and the battle is fought mainly on the field of price.

The struggle for ever lower prices, along with the inaccessibility of the private household as a workplace to controls has brought the 24-hours-care into the spotlight of state legislation. In order to make the labour force from abroad more “visible” for the authorities, a legal distinction between care worker and agency was introduced in spring 2015. The women are now supposed to work on an Austrian business permit and are therefore freelancers. They pay fees and taxes to the Austrian trade office, and social security. That way, they are dragged out of the spheres of influence of the agencies to a certain degree. At the same time, this regulation spares families the burden of employing their helpers and thus granting them employment rights. (One might, of course, question how much of a freelance work this really is, since the agency still determines time, place and duration of any work activity and does not allow care workers to order others to replace them.) In the beginning of 2016, another initiative about transparency and minimum standards for care work providers has been put into place. The bill contains regulations for the contracts between care worker, client and agency, duty to inform extensively about the price, payment methods (in cash to the care worker), and notice periods. These regulations do not yet apply to the agencies that are registered abroad, but still, many of them do already fulfil most of the requirements (Schön/Sperlich/Neumann/Somlyay 2014, leaflet by Wirtschaftskammern Österreichs Gründerservice 2016).

Despite these recurrent attempts to regulate and administer the “chaos” in 24 hour care, the sector is always confronted with an accusation of intransparency, illegality and doing ‘shady business’. Agencies, like brokers of migration in general, are confronted with the suspicion of knowingly predating clients and care workers for their own profit (Lindquist 2015). This is why promoting properness, legality and personal contact makes up for a big part of many agency’s marketing strategy.
Existential exposure as leading principle for care work

The agencies are confronted with a rigid legal framework and, at the same time, the suspicion of neglecting it. On top of that, they have to counter the wide-spread notion that “the sale of care services within capitalist markets necessarily pollutes the authenticity of caring emotions and relationships” (Buch 2014:606). I found that throughout the recruitment process, agencies put particular emphasis on transparency and personal commitment and introduce care workers to a mode of carrying out care work that relies heavily on their own emotional instincts. The relationship between the managers and the managed which is introduced in this first encounter reminds me of forms of modern management in the upcoming “just be yourself” corporation. Peter Fleming studied HR strategies in call centres in an article from 2013 titled “When life goes to work” and noticed the trend to blur the traditional line between work and leisure. Managers incorporate more and more features of leisure time into the workspace while encouraging employees to incorporate more aspects of their selves into productive work, in what he calls moments of existential exposure (Fleming 2013:59). Comparable techniques can be found in the management of care work. Here, it is the authenticity of emotions such as love and empathy that are usually found in the private sphere which agents strive to access. They favour contestants who are willing to this kind of commitment and enhance and encourage them to dedicate their full personality to the work with the elderly people in a different country.

This strategy might seem obvious, but it doesn’t go without saying. Anthropologists have discovered differing modes of managing emotions in the work space, especially in the service sector. Arlie Hochschild (2012), for instance, discovered that many flight attendants only pretend to be polite and good-humored while distancin themselves internally. The “actresses” even experience less emotional stress than their colleagues, who talk themselves into believing that the friendliness they are sharing is real and heartfelt. On the topic of Peruvian care workers in the US, Karsten Paerregaard (2012) noticed that too much intimacy between the care workers and their protégées was feared and sanctioned by their employers, as it turned the paid assistant into a competitor for their “real” close ones.

In the competition of detachment and immersion as possible leading principle for care work tasks, the agencies I got to know vouched for the latter. I am going to show how they frame exposure as a commercially and emotionally superior approach to elderly care work.

“We just want to get to know you”: assessing personal qualities

The agency that will now be described at close range is a medium sized business in an East Slovak town, with a staff of eight being in charge of roughly 200 Austrian clients and 400 Slovak care workers. The staff took pride in their careful recruitment process which played an important role in their marketing strategy. On their website, they claim the following: ‘For your advantage, our specialist staff examines the care workers closely, in terms of their professional qualification and personality, their motivation, thinking, and family background. We handle the selection of care workers with great care.’ This little extract shows that the agency’s assessment of their aspiring partners reaches far beyond their work experiences and seeks for aspects that stem from their private lives. The selection is made during the “instruktaž”, the assessment day which takes place every Thursday and consists of a selective and an instructive part. The interviews are conducted by one of two managers of the agency who I
will call Ms Dukova, an elegant and energetic woman in her fifties. She joins the applicants in an office space with a fashionable delay of 10 minutes. Next to the door of the small training room are big posters with pictures of the care workers with their clients, often even with the whole family, smiling happily into the camera and conveying an atmosphere of mutual trust and harmony. One of the posters states: ‘A person is valued by what he does for others’, the other one reads ‘The love we give to others will always come back to us’ - aphorisms that romanticize the allegedly meaningful and fulfilling character of the work the contestants are about to carry out.

Two women have come to the instruction today. One of them is 32 years old and mother to an 11-year old son. She used to be married but divorced 6 years ago. Throughout the day, she gives a rather quiet and introvert impression, however she stresses the strength and confidence her not-so easy fate has given her. ‘You can manage everything’ seems to be her mantra. The second lady is much more talkative, she interrupts the manager’s speech regularly with more or less related accounts. She is also divorced with kids; she has a diploma in economy but has been unemployed during the last few years. Neither of the women have previous experience with professional caring, except the 2-week internship which necessarily completes the 2-month care work course which all contestants are supposed to attend before going abroad. Ms Dukova tries to convey a friendly atmosphere and soothes the anxious applicants. ‘Are you nervous? There’s no reason to be. We just want to get to know you’, she tells them with a friendly smile. The selection process starts with a questionnaire which confronts the women with critical situations that might appear in the everyday of a care worker and asks for their reaction. In the succeeding individual interviews, they are asked to elaborate on their answers. One of the questions sounds: ‘The person you care for accuses you in front of family members of insufficient care. What do you do?’ In response to this question, both women start to elaborate a defensive speech, drawing the family member’s attention to the work they have done around the house. ‘And do you know what’s the right answer?’, Ms Dukova replies calmly. ‘Don’t defend yourself. The family is not stupid, they see that you have done all these things. The best solution would be to say „Okay, I’ll try to do better in the future“ with a wink. That way you don’t only appease the person who needs care, you also show the family that you understand the patient’s condition and that you have a sense of humour’. In the respective conversations, this solution created an ‘aha’-moment in which the applicants had to acknowledge their potential future employers’ lead in knowledge. The way the interview is designed and carried out demonstrates that an assessment of the care workers’ expertise isn’t the primary goal. The questions do serve as a starting point for a conversation. But in the first place, they are already a means of instruction, teaching the aspiring care workers about the behaviour and attitude that is expected of them in their job.

Following the personal interviews, the German-speaking employees test the applicants’ language proficiency; then the employees meet with the manager to exchange their thoughts and opinions. The quiet lady has left a prevailingly positive impression: She might be a bit too skromná (humble) and sklamaná (uncomfortable), but she will warm up after some time and give a good care worker. As it comes to the chatty lady, Ms Dukova expresses her strong feelings against her:

The second one certainly not. She is very divná (strange). She talks a lot of strange things… When you’re with an old person, you need to be patient, you must be quiet at some time to understand what they say. (...) We also have to think about whether or not she is telling the truth… See, I have a diploma in psychology. I realize when a
person talks a lot, looks around in the room, avoids looking in your eyes, and just goes on and on on... And then I wonder if she’s making all these things up as she goes.

So, the way the aptitude of the contestants is discussed reveals that agents are looking for certain character traits rather than bullet points in the CV. Candidates who, in the agents’ eyes, lack empathy or give reason to believe that the intentions or emotions they display are not real, are likely to fail in providing the necessary comfort for the person in need of care and are therefore rejected.

“Decorate yourself with patience and kindness”: Teaching frugality

The young mother is thus alone for the second part of the instruction day, the ‘training’. Ms Dukova reads out a handbook with advice for care workers which is the agency’s own publication. It includes the following points:

Decorate yourself with a big amount of patience and kindness. After some time, it will return to you many times over. And don’t save on smiles.

Do not treat the person in need of care as someone whose live is coming to an end. Even elderly people have the desire to live their lives to the fullest. They want to chat, go for walks (...) read the news, play games, or look at pictures from their youth. (...) Oftentimes you will have a good time yourself as well.

These tips are revealing as to what person the care worker should represent in the receiving family. She is expected to transfer emotions like compassion and tenderness, from her private surrounding to the paying customer. The work place should collapse with her own intimate sphere as well as the clients’ and she should even take the same pleasure in their free time activities. At the same time, Ms Dukova warns the aspiring care worker about the limits to authenticity at work, as the following extracts show:

The first stay abroad will seem like a very long time to you, maybe you are not used to being separated from your family. You can experience feelings of discomfort, and it can happen that you struggle with tears, depression or aggression. You mustn’t ever react impulsively, or behave in a hysterical or aggressive way. In such a case, contact a loved person who will cheer you up and help you regain your balance.

Do not try to raise the family’s pity by permanently hinting at your difficult economic situation. We know from experience that this makes the family feel uncomfortable.

The message thus sounds that women are supposed to share genuine feelings, but only of the positive kind. Depression, aggression, and notes from her private live in Slovakia are to be shielded from the old person. Care workers’ prevalent aim is to fit in smoothly, and they must absolutely avoid posing any kind of burden on the family. Remarkable is also how a connection back to the “original” private sphere across the border is forged: The love and support of the care worker’s family are explicitly used by the agency as a source of productivity, by helping women to cope with the potentially draining work routine abroad.

Conclusion

Looking at the recruitment process has revealed what kind of ‘product’ agencies have found to be successful on the market. They strive to meet customers’ expectations of family-like care and counter the negative image of their trade by suggesting to form
real emotional bonds between client and care worker that resemble those in their own circle of family and friends. This objective is helped by the fact that they do their work in a domestic setting, which is automatically associated with intimacy and privacy; more than that, agencies encourage care workers to turn this alien private space into their own, not just to take care, but to care emotionally for the stranger. However, even existential exposure has its boundaries. Peter Fleming remarked that the realization of personal authenticity ends at a certain point, and that point is the ‘limit of capital’ (Fleming 2013:65). If the women are their own selves too much, the objective of the whole operation, the stress of the altruist character of care work, is at stake, for instance when they reveal their own financial interests. The second objection Fleming makes to the displayed philanthropy of this approach also applies to the care work case: it essentially ‘works to detract attention from the controls already in place’ (ibid.). Women who believe in the fulfilling and rewarding effect of affectionate care are more likely to accept even harsh strains and emotional distress in their work every day as a necessary component of selfless care. Praising frugality is thus also a way of the agency to protect itself prophylactically from care workers’ complaints about working conditions or demands in terms of salary.

Considerations about supply and demand aside, agents also promote existential exposure because they consider this approach more psychologically sensible for the women than inner distancing. Many employees of the agencies stressed the charitable character of their business, offering women on the margins of society paid employment and creating an environment where they feel save and supported. This also encloses providing feasible ways of dealing with this unusual work situation. Market oriented rationality and responsibility for their protégés are therefore entwined in intricate ways that are worthy of closer examination.

References


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Notes

1 The findings presented here are an extract of the study for my master’s dissertation “Caring agents: Balancing profit and moral integrity in transnational care work agencies in Slovakia” which was completed in June 2016 and is available at https://www.academia.edu/27037111/CARING_AGENTS_BALANCING_PROFIT_AND_MORAL_INTEGRITY_IN_TRANSNATIONAL_CARE_WORK_AGENCIES_IN_SLOVAKIA

2 Quotes from the agency’s staff, website and documents are originally in Slovak and were translated by me. In order to keep my collocutors anonymous, I do not mention the agency’s name or the website’s domain.
ARTICLE

RELATEDNESS IN PLAY: ELDERLY DANISH PEOPLE AND HOME NURSING

BY BODIL HEDEGAARD LUDVIGSEN

Abstract: In this article I aim to explore the phenomenon that home nursing and home care, helps develop essential social relations between elderly people and the professional staff who provides this care. I intend to show that elderly Danish people receiving home nursing create relatedness with home nurses and other professionals (and vice-versa) by assisting the elderly over time in their homes with nursing, care, and other needed practical tasks. The article elaborates on how this happens and what such a phenomenon may entail.

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Introduction

Old and frail people diagnosed with several illnesses and living alone need assistance and support from their family, networks and the welfare state.

In Denmark eldercare is to a high degree performed by professional staff employed by the local council. The universal Danish welfare state, in the shape of home nurses or other professionals, entering the private sphere and home of elderly people offering care work, implies closeness of the welfare state for elderly Danish citizens. Receiving professional help however, also entails assessment and complying with responsibilities and obligations. Living alone and being frail with several illnesses and diagnoses not only necessitates receiving support, care, and home nursing, it also entails supervision and assessment. A contact that creates social relations with professionals coming to help, enabling a smooth encounter and interaction between the elderly person and the professional, a process both parties want to facilitate.

During my fieldwork among elderly people receiving home nursing and in a home nursing ward in Denmark, it struck me that elderly people meet professional staff in a confident and friendly manner, despite having no prior knowledge of the specific individual (Ludvigsen 2014).

The provision of nursing and care work for fragile elderly Danes living in their homes is the obligation of the state following a needs assessment, performed by local councils. This is a provision that is offered cost free at the point of care by staff employed by local authorities. This transforms home nurses and other professionals into important caregivers for elderly people. Elderly people often tend to gradually lose their spouse, kin and friends – social relations that may not be replaced, as fragile elderly frequently have mobility issues and consequently are unable to leave their
home. My study took place among elderly people receiving home nursing, and it was common for the elderly not merely to receive organised care and home nursing, but also that nurses and other professional staff develop into essential social relations for the elderly homecare receivers.

Several scholars indicate that Danish people in general have confidence in- and routinely perceive their relationship with the state as nonthreatening, kind and fairly successful (Jenkins 2012: 169, Gundelach 2004). Jenkins suggests that the Danish state is considered unobtrusive, much like a good neighbor using the expression the ‘state-next-door’. Gullestad points to an understanding and practice (in Norway) of building relational bridges between the institutional life of children in nursery and the life they live in their homes with parents, relatives and friends (Gullestad 1991). Building on these studies, the intention is to bring the concept of relatedness into play by looking at the intersection of elderly people, the state / council and home care.

Methods and informants

The article is built on a study, which was part of Centre for Healthy Aging, Programme 4 focusing on society, culture, and preventive medicine.1 The findings discussed here are based on anthropological fieldwork in a local council near Copenhagen, where I followed, interviewed and carried out participant observation with 15 elderly people. I met the informants, aged 58-95 years (average 86), on 2-8 occasions (average 5 times) over a period of 6-18 months. Additionally, I conducted interview with another nine elderly people once only. The study focused on elderly people’s medication, health activities, everyday life, social relations and who influenced their health concerns and adjustments to changing life circumstances, in addition to their thoughts about death. The fieldwork also included interviews with home nurses, participant observation on their home visits to other citizens, and interviews with relatives of the elderly informants.

The participating elderly citizens all received home care and home nursing for their medication, and home nurses helped facilitate my initial contact with elderly people in their homes. Establishing contact with this ‘hard to reach’ group of elderly would have been difficult without ‘gate keepers’, as many spent the majority of their time at home and when going out they generally visit family, neighbour or go shopping. Only two attended day-care centres or other establishments. An introduction by a trusted person, as home nurses explicitly were, was therefore needed to facilitate appointments. None of the participants suffered from memory impairment, although facing poor health faced and several serious diagnoses.

Theoretical background – Cultures of relatedness

Kinship relations have been studied within anthropology since the discipline was first established. As a subject it feel somewhat out of fashion during the 1970’s, before being rediscovered by a new generation of anthropologists in the 1990’s, study for example gay and lesbian kinship, reproductive technologies and gender as ‘a new kinship’ (Carsten 2000: 3). In the anthology ‘Cultures of Relatedness’ (Carsten 2000) a new step was taken, simultaneously a renewed departure and a return to comparative roots. As boundaries between the biological and the social are becoming increasingly blurred, an essential theme in the book is the relationship between biology and social relations, considering that kinship and biology (or nature) – used to be recognised as interchangeable in western societies. In this new conceptualization, nature does not disappear, but its grounding function is lost (ibid: 6).
Initially, Carsten indicates that the relationship between biology and the sociality of kinship no longer has a fundamental role. She states, ‘rather than beginning with a domain of kinship already marked out, the authors in this volume describe relatedness in terms of indigenous statements and practices’ (ibid: 3).

When analysing kinship emphasis is placed upon social matters, rules, organisation practices or meanings, according to the specific academic tradition in situ. Being open to indigenous expressions and understandings of being related the authors in the anthology use the word ‘relatedness’ instead of previous definitions or versions of kinship.

The creation and development of relatedness occurs in a dynamic process through basic everyday acts and practices (ibid: 16) e.g. small acts of eating, hospitality, sharing a meal, dropping in for a chat, and being together in the same place for a period of time. Carsten underlines that it is hard to see, what relatedness would be without everyday activities of men and women (ibid: 18).

Building on especially Carsten’s studies of how Malay relatedness is created by ties of procreation and through everyday acts of eating, living together (Carsten 1995, 2004), and other daily activities (Carsten 2000). This paper examines how relatedness is established through everyday practices between elderly people, home nurses and other professionals.

The starting point, however, is the cultural background of the Danish welfare state, to which Danish citizens in general have a close and trustful relationship (Jenkins 2012, Gundelach 2004), principally manifested in the shape of local councils. For most elderly people in this study, this relationship was personalised by nurses and other professionals, through whom the relationship often developed into relatedness with the professionals supporting the elderly citizens in their daily care. This daily support was crucial and necessary for the independent living of the elderly on the other side they also wanted autonomy and self-government. In the following building of the relationship with the Danish state is further described.

Construction of relationship in Danish citizenship – The Danish Welfare State as a family

For citizens in the Danish welfare state a close relationship with the state is a kind of truism, a condition, and also an accepted practice for many Danes, including elderly people. The English sociologist Richard Jenkins, who did fieldwork in a Danish town studying Danish identity and what it means to be Danish; describes this phenomenon using the concept of the state as a good neighbor – ‘state-next-door’. He continues:

However, in Denmark the role of the, even yet decentralised, ‘neighbour state’, in making Danes, who and what they are, is anything but abstract. From inscribing individuals in the Central Person Register at birth, to exercising ultimate control over what they may be called, to monitoring and overseeing their earliest formation as properly socialised, co-operative citizens, who will not stick out of the crowd, the state is directly or indirectly involved in the shaping of identities. In these respects and others the relationship between the Danish state and the civil society, between the public domain and the private, is so close and intimate that it can be difficult to perceive where one begins and the other ends. The state – a neighbour that is ever watchful and interested without necessarily being an interfering busybody – is in most respects welcomed into their lives by a population most of whom are accustomed to enjoying the advantages that it offers (Jenkins, 2011: 199).

The Danish anthropologist Kirsten Hastrup mentions family, home, and welfare state 'as
equal’ in the article ‘The Nordic World’, where the Nordic home is understood as a special phenomenon: ‘The idea of the family as the center of the social world, the ‘home’, proved an apt metaphor also for the modern Nordic welfare states’ (Hastrup 2002: 16).

Several investigations about the Danish welfare system show citizens’ approval and confidence in the way the welfare state works, and that they want to preserve it because of its universal character (Christiansen, Johansen and Petersen 2010: 40, Røstgaard 2009, Velfærdskommissionen 2004: 8, Ældre Sagen 2013: 69).

These theoretical findings relate to the trust and confidence in the welfare state, which the elderly people in the study revealed – as to e.g. being taken care of by the state.

Historically and culturally elderly people in this study lived their childhood in the early stages of the Danish welfare state and their adult life during the developing phase of the welfare system, especially during the 1960-70’s, consequently getting used to its advantages and limitations. Generally, the elderly were grateful for the assistance they received and expressed their loyalty to the state and the welfare system in shape of the local council, although the two political and administrative levels interweaved for the elderly. Modesty was a word that captured the common attitude to material goods and assistance: ‘I’ve got all, I need’. Only few used private companies for cleaning, even though it could be paid for by the welfare system. The elderly explicitly preferred nursing and help provided by the local council, rather than private companies: ‘I’ve thought about it, but they are certainly not any better, and I prefer the council, which I know’, was a common statement², displaying their relationship and trust in the local council. Many of the elderly have lived in the same council for years and, they were knew the politicians, they had lifelong interactions with representatives from the council such as health visitors, teachers and librarians, and now with the current managers of home care.

It was common practice for the elderly to receive home nurses and home helpers from the council, as this was the way the elderly managed daily needs, everyday life and practices – a help made acceptable through habit and tradition, and as friends and family members also receive help. The majority of elderly also received additional help of varying character and amount from families, neighbours and others³, and mostly they were treasured social relations. The exception was elderly who had no family or relatives, or had ongoing conflicts with them. For these elderly people the welfare system, the local council and the professionals gained special importance and meaning, as a relationship they could rely upon. Furthermore, favourite helpers were considered to be a valued social relation. However, such relationships did not take place at weekends or public holidays, where assistance was reduced to the bare minimum, making these days difficult to get through.

Based on these examples, from my research and other studies, I suggest that the elderly citizens in my study create relationship, ties, connection, reliance and loyalty to the welfare system and its manifestations through lifelong involvement and connection with the state and presently relatedness with nurses and home helpers sent by the council. Initially though, many elderly thought it was strange to have unfamiliar people in their home to assist them. In due course, however they got accustomed to and comfortable with it. An old blacksmith and his wife, respectively 94 and 93 years old, with a big family who cared deeply for them and also provided some practical assistance, although not on a daily basis, mentioned that it had taken time and adjustment for them: ‘when someone (home nurse and home helper) from outside suddenly comes searching and rummaging
through in one’s home’. The other added: ‘it was strange though, how quickly one got used to them. Now they are members of the family, when they arrive. We are fully satisfied’.

The construction of relatedness through every-day practices.

During one visit to Bonnie [name changed] in her house, she told me that the male home nurse, Bob, would come today. Bonnie knew Bob from a number of visits and liked him, she thought he was kind and skilled and was looking forward to his arrival. However, it was not Bob who later opened the door, it was Merete, a female home nurse, with whom Bonnie was not acquainted. Merete entered the sitting room, said hello to both of us and immediately added that Bob had the day off, and that Bonnie had to be content with her: ‘I’ll take care of your medicine and put your plaster4 on’. Merete searched for different devices, as they discussed where to position the plaster. With trained fingers she placed the plaster and tidied up while she answered questions about the advantages of this type of plasters and how they worked, adding that it looked as if Bonnie was tolerant of the plaster, and that it worked well on Bonnie’s painful symptoms. To have a quiet working space she went to another room to administer Bonnie’s medicine into small boxes, one for each day and altogether for two weeks. Bonnie had an intake of 15 tablets each morning in addition to a smaller intake of pills in the evenings. After a while the nurse came back asking if everything was all right and to say goodbye; she adjusted Bonnie’s pillow on which she was sitting, and left Bonnie and I to our conversation. Afterwards Bonnie and I talked about the visit, that it was not Bob, as expected, but Merete. Being sent by the council Bonnie immediately accepted Merete as a replacement for Bob; besides Merete turned out to be pleasant too and knew her job.

According to Carsten relatedness is established and developed when people are together, share and perform activities, tasks or processes together over a period of time at the same place (Carsten 1995, 2004). Social relations between the elderly and the nurse were essentially professional and personalised, but not private. A professional and personalised relationship, as I saw it performed, is characterised by professionals showing interest, respect and kindness, for example by asking how a celebration went or other conversation points from previous visits. This took place at the same time as dialogues, consultations and negotiations between the elderly and the nurse (See also Zelizer 2005). The nurse shared who she/he was as a person, mostly trustworthy, but generally the nurses’ own problems, private matters, economics, politics and religion were not debated. The elderly on the other hand, revealed private information to the nurse simply by being in a position of needing assistance. Home nurses’ access to the home of the elderly also transferred information about its resident(s), such as appearance, photos, mess, cleanliness, dirt and odours, in addition to health matters.

In a previous study, I suggested that the analytical concept of relatedness is a useful tool to apply within a professional setting, such as home nursing (Ludvigsen 2006). Relatedness is helpful, despite the fact that it is often generated through activities that tend to be of a more intimate character, such as eating together, living in the same place, sharing economy, possessions and effects, good or bad experiences, and events. Home nurses, however, never ate with the elderly and rarely drank a cup of coffee, but still they shared good, as well as bad health and life experiences with the elderly, and they provided information and useful nursing equipment for the elderly, such as medicine boxes, dressing materials and assistive devices. Home nurses also drew attention to the fact that good social relations facilitated
the nursing processes and consequently ensured that nursing tasks could be performed more smoothly for the elderly and the nurse. During visits I frequently saw this take place. The elderly and the home nurses created relatedness by being together in the elderly person’s home for a shorter or longer period of time as they talked, listened to each other, shared experiences, gave and received advice, while the nurses performed nursing care for the elderly in question. In the meeting between Bonnie and Merete, who met each other for the first time, the encounter was facilitated by Bonnie’s confidence in other nurses and the council, and that the nurse acted accommodating.

The elderly who received visits from the home nurse for the first time were often just discharged from hospital and knew neither the person who came to nurse them, nor what to expect. Hence, the first meeting was important and home nurses allowed additional time in order to become acquainted with the elderly and enable dialogue. Most elderly said that they deliberately met professionals in a friendly manner. According to both parties, prolonged and repeated contact generally led to closer and more trustful relationships, as the actors got to know each other. Through dialogue, small talk, physical proximity and touch of the elderly people’s body parts, for example, when nurses carried out treatments, injections and changed dressings, the elderly and the nurse developed a kind of intimacy, closeness, understanding, and consequently relatedness.

Applying the concept of relatedness offers new perspectives, aspects and dimensions, examining not only the relationship between elderly people and the professionals, but also the Danish welfare state.

Outline of a conclusion – Implications of creating relatedness between elderly and professionals

Being a citizen in a welfare state implies conforming to rights, duties and demands from the society, and older people comply and act in accordance to this as well. Furthermore, expectations of the welfare state concerning elderly people are currently being redefined, made explicit and intensified to staying as healthy as possible.

The expression ‘state-next-door’ reveals the closeness of the welfare state for Danish citizens including elderly people. Receiving nursing around the clock and practical help may well be understood as the ‘neighbour’s moving into the home of the elderly, and as indicated above relatedness between the elderly, nurse and other professionals is created by performing tasks during repeated visits in the home. However, having the welfare state within one’s home, in shape of professionals, may result in and produce expectations, duties, dependency and conforming to demands.

The elderly people in this study thought of themselves explicitly as independent and free citizens and wanted to stay so, despite being old and at times rather frail and in poor health. As a citizen in a welfare state most of the elderly felt obliged to look after their health – which among other things meant being physical active, eating the ‘right’ meals, taking their medicine as prescribed, and not least adapting to their current life conditions. Furthermore, the Danish way of understanding and interpreting the welfare state, including the obligations of citizens, is entrenched in the perception of how citizenship emerge, for example how to participate, adapt, collaborate and integrate (Ministeriet for Flygtninge, Indvandrere og Integration 2011: 29). For the elderly that also meant being cooperative when receiving professional helpers and establishing good social relations with them. On the other hand, complying with these demands made the elderly feel integrated, included and a
member of the society – in addition to establishing relatedness with professionals.

My fieldwork showed that only limited misunderstandings emerge when the elderly and the nurse or other professionals were on good terms with each other. The nurses claimed they did not control nor watch over the elderly; nevertheless they carried out observations or supervision in a discreet professional manner, which the elderly perceived as care and interest from a nurse they knew, and in whom they had confidence. Modern forms of state power are nearly invisible, Michel Foucault calls it pastoral power (Foucault 1982), and the Danish historian Signild Vallgårda suggests that through the health care system: ‘Doctors, nurses, and midwives could be said to exercise such pastoral power by gathering information about each individual in order to ensure that individual’s salvation in this world, i.e. his or her health’ (Vallgårda 2011: 32).

The elderly persons’ fight to be included took place through creating relatedness, integrative processes, and ‘to do what I’m told’, as one of the elderly people said, hence trying to adapt to own demands and the expectations of relatives, professionals, as well as the welfare state. The elderly wanted to be a part of the society, and they went far to maintain this wish. The efforts of the elderly people materialised by a nearly 100% intake of the prescribed medication, persistent struggle to maintain health by physical activity and training, and by maintaining good social relations with the council and the professionals, which was the field of possibility the elderly had to preserve health and inclusion – together with help from relatives for those who could rely on this.

The lifelong relationship with the Danish welfare state and the relatedness that was created with professionals gave the elderly inclusion, support and help. On the other hand, this relationship and relatedness obliged the elderly to comply with anticipations, duties and demands.

References


Notes

1 Centre for Healthy Aging focuses on research into aging for better health and reduced frailty throughout life. The multidisciplinary programmes investigate biomedical, social and psychological causes of healthy aging. The centre consisted at that time of 5 programmes. Programme 4 ‘Society and Culture: Health Care Policy and Preventive Medicine’ focuses on analysis of health policies, organisation of the health care system, and medical technologies available for use in preventive medication. The centre started its activities in January 2009; in 2014 the activities were reorganised. It is administratively placed under the Faculty of Health Sciences, University of Copenhagen, and was established through a donation from Nordea-fonden to the University of Copenhagen. The donation was renewed in 2014: Please see: http://healthyaging.ku.dk/

2 This finding was consistent with the Dutch philosophers Andries Baart and Francis Vosman’s analysis of care of very old people in Western societies. Baart and Vosman drew attention to a difference between the 65 – 80 years old and the very old 80+. According to them, the oldest group (80+) needed more help than the younger group (65-80), as they were less likely to be in good health, energetic, self-confident and independent with a purposeful understanding of their life project: ‘The very old do not fit into the scheme of autonomous and self-conscious clients, who buy the care and cure, they wish to be given. The very old do not fit into the autonomous model of human existence, with its concurrent claims about freedom of choice and the unencumbered self’ (Baart & Vosman 2008: 22)

3 The Danish researcher Tine Rostgaard studied how Danish families are involved in care of their elderly relatives and shows that the Danish state is the main caregiver of elderly’s daily care and needs. Merely 17% of elderly Danish people receive sole help from relatives, compared to 54% of Swedish people. Families tend to take care of more sporadic tasks. Rostgaard also shows that this is the model most people (elderly people, as well as relatives) prefer (Rostgaard 2009), other investigations show the same pattern (Ældre Sagen 2013)

4 Special plaster, where the surface contains painkillers.
ARTICLE

WHEN CARE STRIKES BACK – SOME STRATEGIES AND TACTICS FOR DEALING WITH AMBIVALENCE OF VISIBILITY IN CHRONIC ILLNESS

BY STEFAN REINSCH, JÖRG NIEWÖHNER & DORIS STAAB

Abstract: Building on the works of sociologists of health and illness that have highlighted the effects of visible difference and stigmatisation since Goffman, this article examines the ambivalence of visibility experienced by people with cystic fibrosis (CF), a fatal chronic disease and the artful tactics they employ in carving out a habitable space in an ableist world. Dealing with the ambivalence of being at once inherently ill and apparently healthy is a process of giving constant care and attention to one’s body and its presence in public, and if successful, enabling those affected by it to acquire a new - albeit temporary - healthy self with the help of therapy.

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Introduction

Anthropologists have directed our attention to the struggles of marginalized individuals and groups like those with a chronic illnesses to gain greater public visibility of their therapeutic burden. Yet, only modest attention has been paid to the efforts put into achieving a visible normality through therapeutic practices or to the therapeutic work behind this apparent normality (Robbins 2013; Ortner 2016).

We present here the results of a longterm anthropological study in collaboration with a group of adolescents and young adults who have cystic fibrosis, a fatal genetic condition. Through fieldwork in Berlin, Germany, we explored how young people – who often do not readily appear to be sick – integrate therapy into their daily lives (Jorgenson 1989).

Building on the works of sociologists of health and illness that have highlighted the effects of visible difference and stigmatisation (Goffman 1969; Yang, Kleinman, Link et al. 2006), this article examines the ambivalence of visibility experienced by people with CF. We extend the conceptual framework put forward by Michel de Certeau (1980) in his studies of the practices of everyday life of marginalized people to those living with a chronic illness to show the artful tactics they employ in carving out a habitable space in an ableist world.

We follow the story of a group of young people we met in 2007 at an outpatient clinic,
and re-encountered several times over the last 10 years. As both anthropologists and doctors, we are interested in their struggle for well-being, care and with morality (Mijazaki 2004).

Living with CF

It was a warm summer day in Berlin. Tanja (a pseudonym) and I met at a photography exhibit in the city centre. She was one of the young adults with Cystic Fibrosis we followed in the course of our research. At the entrance to the exhibit, Tanja flashed her disability card and asked for free entry for herself and one of us as her “accompanying person”. The young man at the desk looked at Tanja with hesitation, his eyes moving between Tanja and the card she held in her hand. He seemed to be assessing whether Tanja was attempting to elicit a benefit to which she was not entitled. Tanja was an good-looking young woman in her early twenties. She spoke quickly and confidently in a way that troubles categorizations like healthy/ill, able/disabled, and the tendency to equate illness and unattractiveness (Hall 1997). Tanja didn’t fit the stereotypical image of a disabled person who requires someone to accompany her. By using the card, she transgressed forms and expectations, rendering her in some ways unintelligible and difficult to “sort out” (Bowker & Star 1999). This unintelligibility is a part of the burden of living each day as a young person with a fatal chronic illness (Badlan 2006; Williams et al. 2009)

CF is a rare genetic disease that causes frequent respiratory infections, leading to progressive scarring of the lung tissue. Most people with CF will start their therapy in the first years of life and will require a lung transplant at some point in their lives; those who do not receive a transplant often die from suffocation. There is currently no cure for CF, but its progression can be slowed (Ratjen & Döring, 2003). In Europe and North America, the life expectancy of someone with CF is approximately 38 years and it has been continuously rising in the last decades from around 15 years in the 1960. Responsible for this increasing survival is not a single new drug, but a more complex and demanding therapeutic regimen (Davis 2006; CFF 2009). It involves approximately 2 hours of inhalation and chest physiotherapy every day, and up to 7 different oral medications (Sawicki et al. 2009). Patients consider this therapeutic regime as burdensome and time consuming, and treatment is seen as marker of illness and stigmatising (Bregnballe 2011). Especially for adolescents and young adults it is a continuous challenge to integrate the therapeutic regimen into daily life with school or work, family, friends, and leisure activities (Staab et al 1998). Faced with the possibility to be part of their peers, young people with CF employ an arsenal of tactics to hide the work behind their normal apparence (Ernst, Johnson & Stark 2010).

Adherence to the therapeutic regimes is around 50% (Llorente et al 2008). While poor adherence to this complex therapy is recognised as the main cause of treatment failure and increased exacerbation rates (Eakin et al 2011), some authors suggest that educated non-adherence with a treatment may be an adaptive way of coping (Dodd & Webb 2000). Since nobody is able to be 100% compliant with long-term treatments, it seems reasonable to aim at ‘educated non compliance’, so the patient is capable to decide together with the CF team what is important for him and what could be skipped for a certain time. Patients and caregivers are balancing out which minimal therapy works for them at a certain moment (Havermans & de Boeck 2007).
When care strikes back at normality

The balancing act takes on particular significance if a therapeutic regime is very successful. As one physician told us during an interview:

_There may be moments when doing more therapy leads to better health, and at this point you reduce therapy – because everything goes well. Some patients are then able to lead a life undisturbed by therapy for a period of time. In such a moment of relative stable health even very little therapy can be very disruptive._

In the last case referred to by the physician, the effect of increased therapy levels off and reaches a plateau. Economists would say from a certain point onwards, extra treatment has decreasing marginal utility. Patients whose health-state demands for a treatment burden beyond this plateau experience a double bind, like one of Tanya’s friends:

_When I was still at primary school, some teachers sent me home when I was coughing, saying “come back when you are healthy”. But I would still be ill in a week! So, I realised that I didn’t have to cough as much if I didn’t inhale in the morning. Smart, aren’t I?_

The dynamic described by Tanja’s friend is experienced by many other patients as 'normality striking back at therapy'. To appear normal in a period of relatively stable health, therapy has to be absent. Although the young patient did her inhalation at home, she was still ill to her peers and teachers when she coughed in school. As coughing made her illness apparent, the therapy didn’t work at that moment. Even if it would lead to better health in the long term, the adverse effect of inhalation therapy made illness visible. When more treatment leads to more symptoms, while less treatment leads to greater chances to spend time on activities with peers, skipping therapy seemed a rational choice.

People in such a situation will generally want their condition to be invisible to the public. As they are at constant risk of outing themselves involuntarily, they have developed an arsenal of strategies for passing (Goffman 1963). Through therapy, they can render their illness invisible to the general public. Their illness is of course perceptible to themselves and to their doctors, and perhaps other patients. Some subtle signs like clubbing of the fingers that indicates lack of oxygen, a hump in the back that hints to overinflation of the lungs, a hoarse voice from inhaling and the salty taste when you kiss someone with CF will be put together by people that Goffman (1969) called “the wise” - those that know the signs of an affliction by acquaintance.

The difficulties related by the to “sort out” Tanja at the exhibition, or her friend at school reveals their double status as someone who is at once ill and apparently healthy (Bowker & Star 1999), but also the possibility to manage this double status by tactically revealing either status.

CF therapy has traditionally taken place in hospitals. But, increasingly, the space of therapy is becoming fluid. With the help of procedures like inhalation, chest physiotherapy and the delivery of intravenous (IV) antibiotics, patients have gained opportunities. For this to occur, certain technical innovations were essential – such as replacing the standard and somewhat clumsy hospital infusion pump with a smaller one. Patients can slip this smaller pump into a trouser pocket, running the IV line under their shirtsleeve. Moving therapy out of the hospital means greater freedom for patients living with CF, but it also means that they have to integrate therapy into the practices of everyday life, particularly at home.
Strategies and Tactics for managing the visibility of illness and therapy

We follow here Michel de Certeau who differentiated tactics from strategies. Strategies are calculation of power relations that require a place, a basis for organising relations, while tactics cannot calculate with a won space, but have to use the space of the other, and cannot capitalise gains. A hospital or a research laboratory would be such places where doctors and patients can strategically develop and test therapies, devices or drugs. Outside a hospital, patients are only able to deploy their tactics at a “right moment” in order to control illness and its visibility. Since tactics cannot be planned in advance, they require experience to recognise and capture the “right moment”. While strategies are dependent on the use of a place, tactics are dependent on the use of time (de Certeau 1980:23).

One frequently employed tactic is to disclose illness only to certain people. Knowledge about CF would be shared with close friends only and only rarely to casual encounters – like Tanja at the museum (Borschuk et al. 2016). Differential disclosure is employed to mitigate negative repercussions or negative consequences when disclosing to romantic partners and in the workplace (Modi et al. 2010) As Tanja explained „Emotions are quite strong, I’ve been able to suppress the urge to cough for a really long time, when I came home at night with someone I didn’t want to know of my CF.” While it is assumed that greater disclosure is associated with higher disease severity (Lowton 2004), here, we attempt a more fine grained analysis. Almost all patients we have worked with oscillate in their relation to CF. ‘Being normal’ and ‘doing therapy’ are modularised in space and time so as to manage their therapy in a way that CF does not reappear in public. While it is not possible to observe that in casual or clinical settings, participant observation at patients homes provided insights into how patients manage this. The remainder of this article is illustrating that way of coping.

In Tanja’s apartment, a handful of pills lay on the kitchen table. I recognized them as the pancreatic enzymes many young people with CF have to take with every meal so that they can absorb nutrients. On a nearby shelf, there were boxes of vitamins, anti-inflammatory drugs and antibiotics. Another box of antibiotics sat next to the cheese in the fridge. Beside a bookshelf was Tanja’s nebulizer, a handheld device the size of a small bottle. Through a mouthpiece on its top, Tanja inhales hypertonic saline for up to 30 minutes, two sessions per day in order to dilute the mucus that builds up in her lungs.

On one of the many occasions when Tanja’s physiotherapist visited, talking was also part of the session. The two of them began by catching up on the latest news and events: patients who had gotten better lately or taken a turn for the worse, and their holiday plans. Only after socializing did Tanja lie down on the couch to begin chest-physiotherapy, a procedure that involves chest compression and decompression to mobilizes the mucus in the lungs that can then be coughed up slowly (image 2). During the treatment, Tanja’s face became red and the room was silent except for her repeated coughing. These moments of coughing were a stark contrast to the casual social encounter that began the 30 minute long session; suddenly, Tanja’s illness was starkly present. But, after one seemingly endless minute of exertion, Tanja spat the mucus into a small sealable container and the chatting continued.

As in during the physiotherapy session, there is a constant blurring of lines between therapy and everyday life for young people living with CF today. Tanja and others
described to me how the dramatic intensity of life with CF can lead to close relationships. Many patients have relationships with other patients, and sometimes marry. Patients and medical staff like to go to exhibitions and concerts or on vacations together. One doctor remembered being called on the phone in the middle of the night by a patient who had gotten lost on the highway while hitchhiking. Although initially patients like to keep distance between the hospital world and day to day life, with time they become increasingly entangled.

But the value of participant observation based research are close relationships and a becomming with participants (Ingold 2013). At the beginning of this project, I was warned by the staff at the CF clinic that they have seen several of their younger doctors become emotionally attached to patients who later died. During the first year of research, three of the 15 patients I followed passed away and several have since during attempted lung-transplantation or while waiting for one. But the close relationships that were formed with some of the young adults we followed were fundamental to our anthropological work – and in some ways difficult to avoid in a research envisioned as a collaborative process. We were similar in age and interests to many of our collaborators; they, in turn, were often enthusiastic about reflecting on the ambivalence of their visibility in the context of our work together.

That same night when her physiotherapist had visited, Tanja came out of her room before bed to put a gastric tube through her nose. She connected it to a bag of high-caloric food to ingest into her stomach while she sleeps. These extra calories are essential to meeting the increased energy demands experienced by people with CF, who experience a constant inflammation as a result of fighting chronic respiratory infections and generally have to work harder to breath. The gastric tube is not a comfortable procedure; in fact, Tanja knows of only few other people who do it. “I also usually do not show this to anyone,” she laughs. Doing but not showing is what allows her to be normal most of the time. While spending time with patients, it was sometimes hard to notice them doing any therapy at all over a day. Some strategies resemble technical fixes, like having a port inserted instead of an i.v. access or taking cortisone before going to nightclubs, where cigarette smoke could trigger a bronchial hyperreagibility and lead to the constriction of the airways.

Some of the tactics they employ are quick cover-ups, like stuffing pills directly into a sandwich instead of taking them with liquids during a meal. Other tactics resemble Mimikri, for example using explanations like „It's sth. like Asthma“, a trope frequently employed by several of our collaborators when they were asked why they coughed instead of explaining CF. During those times when she needs IV antibiotics, Tanja would make the cotton covering the IV line on her forearm a little thicker, transforming it into a “sweat band” so that the line wouldn't be as visible. One day, she and a friend were asked about those „sweat bands“, while at a hairdresser who remarked that they had an iv line underneath them. Tanjas friend told us the hairdresser had inquired if they were taking methadone because they looked so pale. She sighed, stating that being taken for one who is on a drug replacement programm which is clearly stigmatizing was still better then explaining CF to a casual encounter. Table 1 lists some strategies and tactics we found.

Some challenges can be fixed using clever tactics, some by medical progress and some cannot be fixed at all. For some situations, like the direct transfer of oxygen to the lungs, which some patients require, such quick cover-ups and mimicries cannot be applied.
Inhalations need time to prepare and to be carried out. To clear the mucus, mobilised by inhaling, one needs to cough afterwards, because of the urge to do so caused by inhaling and because without coughing the mucus out, inhaling is considered medically useless.

The strategies and tactics work out quite well most of the time, but they are precarious, and can fail at exactly the wrong moment, as we will see in the next section.

Table 1. Strategies and Tactics for managing the visibility of illness and therapy

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technical fixes</td>
<td>Smaller infusion pumps, port systems, gene-repair drugs (ivacaftor)</td>
</tr>
<tr>
<td>Tactics</td>
<td></td>
</tr>
<tr>
<td>Non-adherence</td>
<td>Inhaling less in order to avoid prolonged coughing in public.</td>
</tr>
<tr>
<td>Differential disclosure</td>
<td>Using different levels of involvement and disclosure, like telling romantic partners and friends but not your boss.</td>
</tr>
<tr>
<td>Oscillation</td>
<td>Switching between relating to CF as therapy being normal</td>
</tr>
<tr>
<td>Mimicry</td>
<td>Using explanations like „It's sth. like Asthma“, accepting being taken as on a drug replacement program instead of explaining CF iv-therapy.</td>
</tr>
</tbody>
</table>

When tactics fail: dealing with the ambivalence

What enables patients to participate in an apparently normal way is a permanent gestalt-switch between relating to CF as 'therapy' or being normal. Problems with this arise when an element causes a gestalt-switch at a wrong moment: One day a friend of Tanja who was studying medicine slipped away at the break during a seminar at the hospital to get an i.v. line for her home antibiotic therapy. The old i.v. was clogged and she needed a new one quickly in order to get back to her seminar before it started again, so no one would ask questions. To repair it she had to improvise a 'hospital setting'. She went to get a new i.v. line on the ward and found someone to put it in place. But doing this during a short seminar break, time is of the essence. Placing a i.v. in a CF patient often requires patience. The aggressive antibiotics used to combat infection make it more difficult to find a good vein after each therapy round. At that very moment, no doctor had time. So another patient, who was also a doctor was recruited for the procedure. Straight afterwards, the moment she slides the infusion pump into her pocket, she is back to normal. It seems as if she is carrying the hospital in her pocket.
This requires a lot of work, and it is risky. If it becomes apparent that one has an infusion pump in the pocket, all the skilful work of concealing will be futile. The desire to appear normal is so strong, that there are moments where patients would rather run the risk of seriously deteriorating their health than to disclose being ill through doing therapy.

The next morning, after Tanja used her inhalation machine for half an hour while reading a book, we drove by the office were she had worked until recently. She recalled, “At work I had to justify myself whenever I was late – that I just did my inhalations and wasn’t lazy. It’s difficult to explain every time – even some people who work with you don’t seem to understand.” Tanja remembered a colleague who had told her about how one of his acquaintances had gotten a renal transplant, and how horrible that idea was to him. “I was struck with disbelief”, Tanja said, shaking her head. “I told him I might need a lung transplant in the not so distant future. He didn’t get it – perhaps I still look too good?”

The more therapy young people like Tanja do, the better they look. But the better they look, the higher people’s expectations are regarding their level of functioning. As one of Tanja's friends, who is still working, told me during an interview:

I consider doing my therapy, in the way that it now fits into my life, as a disadvantage, because you don’t belong to any group. You are not part of the ill ones...but neither are you part of the healthy ones. That makes it difficult, because you have to justify yourself whenever you try to integrate yourself [into either group]. You are not part of any group, and you have to excuse yourself for what you don’t have – illness or health.

Immigrants to health

As Kaufman (2010) has argued, in cases of serious and chronic illness, clinical practices contain the challenges for those who are ill to imagine certain kinds of futures in which one’s corporeality is central, and to choose among medical options in order to move toward one kind of future instead of others. The logic that places the needs of acute everyday life above long-term survival is deeply embedded in the social practices of an ableist society (Maynard 2006). Patients with a chronic condition do not want to survive, they want to live. Living with CF means dealing with ambivalence of visibility since, while visibility of illness excludes them from the group of the healthy ones, it is also a resource that can be used to gain support and care. Yet, this ambivalence can only be navigated purposefully to a certain extent. To many outstanders, the double status of someone with CF – who is at once inherently ill and apparently healthy – is un-intelligibility. Most will try to sort them into either group.

The German philosopher Hans-Georg Gadamer (1993:171) romantically said that health is equal to a “self-forgotten state of abandonment to the future”. Kathy Charmaz (1981) once argued the experience of chronic illness to be a loss of self. As this paper has tried to show, those with a chronic condition like CF, who have 'never not had it' cannot be said to experience a loss of a healthy self (Williams 2009). Neither are they self forgotten. Being alive for them is a state of constant attention to their self and its presence in public, rehearsing their arsenal of tactics of disclosure and mimicry and oscillating between being normal and doing therapy.

This constant oscillation between normality and therapy is line with an argument by Joseph Dumit (2002) who observes that since the 1990s the paradigm of “inherent health” and illness as deviation from the norm has been replaced by a notion of illness in which bodies are inherently ill and a precarious self
arises that needs constant maintenance to keep symptoms at acceptable levels. Dumit proposes that through the treatment of a chronic disease, a precarious self arises that needs constant maintenance to keep symptoms at acceptable levels. The new 'normality' is thus not a return to the previous set of symptoms, but a 'virtual normality that is dependent upon medication'.

We would like to extend Dumit's proposition. With the help of a very complex and demanding therapeutic regimen, people with CF are able to make the symptoms of their illness invisible, thus allowing them to acquire a new – albeit temporary – healthy self. They become 'immigrants to health', to turn around Susan Sontag's (1978) phrase. Acknowledging the burden of therapy they face, and claiming the kinds of social support to which they are entitled as 'disabled' persons, may come with the loss of a sense of belonging in the world of the able bodied. This was a kind of temporary citizenship that many young people deeply desired.

References


Abstract: Respecting patients’ choices is an increasingly celebrated ideal in healthcare. If this logic of choice is absent – the argument goes – care is just a form of force enacted on patients by healthcare professionals. Drawing from the existing literature and from fieldwork in a treatment centre for Eating Disorders in Italy, this paper shows how it is necessary to disentangle the idea of good care from its immediate association with patient choice. Since for these patients will is complexly entangled with need, good care here means being able to enact the practical requirements of care even when patients, at that very moment, would refuse them. The key issue is the modality in which caregivers do this: the kind of affection, dedication and ‘being present’ that they display.

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Introduction – Logic of Choice vs. Logic of Care

Individual choice – and the entitlement that patients have to choose as regards their own treatment – is an increasingly celebrated ideal in healthcare. Patient choice is seen as the paradigm towards which we should all tend, while trying to move away from treatment practices that are now framed under the notion of force. If this logic of choice is absent – the argument goes – care is just a ‘soft form of force’ enacted on patients by healthcare professionals (Mol 2008: 1-3). Mol has widely written on the risk of mobilizing a logic of choice without considering the specificities and intricacies of the illness in question. She shows how in the case of Diabetes a logic of choice easily leads to poor care, since it does not liberate patients from the passivity in which they are supposedly forced, while shifting the weight of what goes wrong on the patient’s shoulders. For this reason, she calls instead for mobilizing a ‘logic of care’ (Mol 2008: 8,9).

Drawing from the existing literature and from fieldwork in a residential treatment centre for Eating Disorders in Italy, this paper will unravel ‘the specificities of care’ with reference to the daily life of patients with Eating Disorders, and show how it is possible – and necessary – to disentangle the idea of good care from its immediate association with patient choice and ‘tender love’ (Mol 2008: 2,5). These elements are not irrelevant in the care of Eating Disorders; on the contrary, they are fundamental. However, as long as good
care is associated with patient choice and tender love, it can be framed as something opposed to what are actually good treatment practices. In the case of Eating Disorders, good care is definitely something that cannot be forced on patients. Force here does not work. But neither does patient choice.

In her ethnography about Diabetes treatment, Mol (2008) points out that in care there is not only a contrast between ‘choice’ and ‘no choice’, but also between these two, united in a logic of choice, and a different alternative, that of care, which is in contrast with neglect. She brings the example of a psychiatric patient who does not want to get out of bed in the morning and go to breakfast. If healthcare professionals were supposed to act following a logic of choice, i.e. to respect the patient’s desire, they would have to leave him in bed. Which in the case of someone suffering from a psychiatric condition such as depression might well mean all day. It is not easy to disagree with the observation that the patient in question would not be receiving what one imagines as good care. But how to define good care? The problem is that the ideal of good care is incorporated into practices and does not speak for itself: the aim then is to articulate its specificities (Mol 2008: 2).

In the logic of choice – Mol explains – the central question is whether people are able to make choices or not: maybe healthy people are, while people with a disease are not; maybe some people with a disease are, but not all of them; or maybe everyone can choose under the right conditions (Mol 2008: 8). This is why instead of focusing on the abilities of people, Mol calls for focusing on the practices in which people are involved; and instead of asking who should make given choices, she calls for taking a step back and for considering in what kinds of practices ‘situations of choice’ do arise (ibid.).

The Logic of Care in Eating Disorders Treatment – Desire and Need

Mol’s argument is definitely relevant to the case of Eating Disorders treatment. Eating Disorders such as Anorexia and Bulimia Nervosa are egosyntonic psychiatric disorders: i.e. the behaviours, values and feelings that stem from the disorder are in harmony with the needs or goals of the patient’s ego, consistent with the patient’s ideal self-image. This means that they are extremely difficult to treat, and that giving a patient suffering from an Eating Disorder the freedom to choose will not help her/him, as this might easily lead to chronicization or even death. Anna Lavis (2016) has recently written a Think Piece that reflects on the desire to maintain an existing illness, based on the narratives of individuals diagnosed with Anorexia Nervosa. Whereas anthropologists have always tended to frame illness experiences as unwanted and undesirable, by considering accounts of individuals living with anorexia Lavis asks instead how anthropology might critically approach illness and its suffering when both are entangled with desire: ‘What forms does the desire to hold onto illness take? What does desire do in the context of living with anorexia? And how might this desire be approached ethically in both anthropological analysis and clinical practice?’ (Lavis 2016: 69).

While many patients suffering from Eating Disorders acknowledge that theirs is a distressful and serious illness, they also express an ambivalent desire to maintain it. Desire has been widely analysed in relation to Eating Disorders, especially in psychoanalytic literature, but this way of thinking privileges the visual rather than the lived body: it frames emaciation as the end goal in Eating Disorders, caused by a desire to return to childhood and/or by the ‘slenderness imperative’ that dominates our society (Bordo 1993). Although highlighting the cultural
context of the illness is important, the focus on emaciation frames the Eating Disorder as a means to a desired end rather than the object of desire itself. Whereas patients’ words – ‘anorexia is just the way I do things’ – call for a shift in analytic perspective, drawing attention to the processual nature of Eating Disorders (Lavis 2016: 70,71).

Individuals suffering from an Eating Disorder often talk about their illness as ‘helpful’ and ‘protective’, as something that ‘looks after you’, communicating the sense of being cared for by the illness. As such, although self-starvation can be clinically framed as an expression of a lack of self-care, informants’ narratives depict it as a modality of self-care that is at the same time a response and precarious solution to pain (Lavis 2016: 71). In a way, therefore, for those with Eating Disorders the eating problem is not the problem, but the solution. It is an attempt to reorganize the self as a possible solution to suffering (Orbach 1993: xxii,xxvi; Marucci and Dalla Ragione 2007: xxiv). Kleinman has argued that caregiving is a basic response to the context of danger and uncertainty that defines the human condition (AAAI Conference, Maynooth 2016); it seems that the same holds for Eating Disorders as a particular and contradictory form of ‘self-care’. Indeed, individuals explain that their feeling of being ‘looked after’ by the illness emerges from the way in which the disorder offers a still and ‘safe’ space, a ‘cloud away from everyone else’. Desire in this case is thus about holding on to an existing illness in order to get through life. The eating disorder offers a way to move through the world by withdrawing from it; this is why individuals know it is harmful, feel it is painful, and yet they may want to maintain it (Lavis 2016: 72). The idea of maintaining the eating disorder as a way of being in the world illuminates how recovery can be frightening, and that holding onto it may have a lot to do with need. This blurring of the boundaries between desire and need shows that ‘desire’ does not adequately take account of the complexity of individuals’ relationships with their illness, and the slippages of agency inherent in these relationships. Holding onto the eating disorder may be something that is wanted and actively worked upon by the individual, but also unwanted and painful at the same time, because it is likely to be about ‘seeking out ways of living within compromised conditions of possibility, rather than an expression of preference’ (Lavis 2016: 72). This calls for an anthropological reconceptualization of desire as not necessarily implying choice or agency, but also ambivalence and need (ibid.). It is in this sense that ‘[...] agency is created, not as an inherent quality of which individuals may have more or less but as an aspect of situations in which people may find themselves, and how this effect is created by attributions of responsibility’ (Laidlaw 2010: 148).

Against this background, the rest of the paper will attempt to explore how the desire to remain ill is and should be engaged within treatment in order to go beyond the binaries of cure vs. treatment failure, and what forms of care such a rethinking might mobilize (Lavis 2016: 73). Where to draw the line between respecting patients and neglecting them by failing to recognize the complex entanglement of their desires and needs? Up to what point should healthcare professionals insist when a patient refuses to eat? But most importantly, how should they insist?

**Nutritional Therapy – When Eating is a Torture (and how to make it less so)**

Harbers, Mol and Stollmeyer (2002), in their work on feeding within the care for the elderly with Dementia, point out the inadequacy of both the ethicists’ ‘will perspective’ and the biomedical ‘natural course perspective’. In the former perspective, not feeding a person who refuses to eat is seen as a way of respecting his/her
will; in the latter, lack of appetite and thirst is seen as a symptom of Dementia. Dementia – the argument goes – is a disease and the need for food and drink disappears as the disease progresses. Therefore if a patient dies as a result of fasting, this should not be understood as a consequence of (lack of) human intervention, but as ‘natural death’ (Harbers, Mol and Stollmeyer 2002: 211). The inadequacy of both perspectives is even more poignant in the case of Eating Disorders. How to talk about ‘will’ and ‘natural course’ in the case of an illness that seems to be so strongly tied to the person’s will – think about the self-discipline that is necessary to fast and overly exercise – but whose ‘natural course’ involves the loss of one’s will under the will of the illness – even once the person has decided that she wants to undergo treatment, she literally cannot eat nor stop exercising unless forced by someone else –?

From this inadequacy comes the need to refer to a third way of relating to patients and their daily lives: this involves a caring relation in which it is important ‘to mean something to someone’ and undesirable to neglect them (Harbers, Mol and Stollmeyer 2002: 211). As in the care for the elderly with Dementia, in the day-to-day care of individuals suffering from Eating Disorders eating and drinking depend on more than just the will of individuals and the natural course of their illness. What matters are the carers, the way they attend to patients, and the ‘materialities’ employed by them in this attending: tables, chairs, plates and food itself. By describing care as ‘a socio-material practice’, it is thus possible to cross the binary between ethical and biomedical versions of ‘the good’ (Harbers, Mol and Stollmeyer 2002: 208,214).

The setting of my fieldwork was a public inpatient treatment centre that I call ‘Palazzo Alberese’, located in a small town in central Italy. It accepts both adolescents and adults with diagnoses of Anorexia and Bulimia Nervosa. The centre employs a multidisciplinary approach that is based on the coordination of psychiatrists, nutritionists, endocrinologists, psychologists, dieticians, philosophers, a dance-movement therapist, a drama therapist, educators and nurses, plus an administrator who deals with insurance coverage and other bureaucratic matters. One of the many care practices that caregivers need to ‘force’ on patients during their stay, the one that is most feared and hated by patients, is nutritional therapy – which is meal times. Meal times in this kind of treatment centres are ‘key events’: they structure the day and its rhythm, but patients are never keen to eat or drink. This is why ‘a system of encouragement’ needs to be in operation, constituted not only by explicit and verbal encouragement, but also by a lot of implicit encouragement incorporated into other ways of caring (Harbers, Mol and Stollmeyer 2002: 216).

First and most visible is the context of nutritional therapy, i.e. the space – both structural and affective space – where patients eat their meals. The list of things that matter is endless: ‘Words of encouragement. The setting of the table…[…] A whole gamut of practicalities, of simultaneously social and material ingredients’ (Harbers, Mol and Stollmeyer 2002: 217). As Harbers and colleagues point out, in both ethical and medical discourses food and drink are seen in an instrumental way; but in a context of care, and especially in a context of care for Eating Disorders, food and drink are not only means for physical survival: ‘They are also media for care – they do care. They taste good or bad, have a nice or gruesome texture. They are, not as delegates of people, but all by themselves, objects of longing or aversion’ (ibid).

The programme explored by Warin in her ethnography of inpatient treatment for Eating Disorders in Canada, for instance, included the condition of eating alone in one’s own room – whose bathroom had been previously
locked to prevent patients from throwing food away or vomiting. The idea here was that patients had to focus on the task of eating with no distractions: ‘No one will be present while patients are eating meals. Meals must be eaten before visitors can be seen and must be completed within 30 minutes. TV and radio to be switched off while eating’ (Warin 2005: 106). Moreover, there was a conflation of practices and spaces, with things normally associated with sociality becoming private: the bedroom, the toilet and the place for eating were the same space. In this way, the single room of the psychiatric ward reproduced the spatial configuration and the social relations that patients had been practicing at home to support their eating disorder, recreating the social isolation that is central to maintaining it. And patients still managed to enact dysfunctional behaviours such as hiding food in the ceiling panels, draining apple juice into bed pans and spreading butter between newspaper sheets or duvet covers (Warin 2005: 105-109). Since Eating Disorders are characterized and sustained by a range of dysfunctional behaviours – eating very little, skipping meals, exercising, binging, purging, taking laxatives and diuretics – most of which are performed in secret, the idea of most treatment regimens – based on behaviour modification – is that intense monitoring and surveillance of patients is absolutely necessary to eliminate such behaviours (Eckermann 1997: 157,158). However, one also has to remember that Eating Disorders themselves are strongly based on self-control and self-surveillance (Bell 2006: 285). It is in this sense that Malson (2008: 27-42) argues that the institutional treatment for anorexia is ‘anorexia-like’: it relies on the same technologies of monitoring as does the illness itself, turning therapeutically intended regimes into anorexogenic environments. And the more treatment is experienced as controlling, with staff mainly having a surveillance role, the higher the risk of rebellion and struggles for control (Ryan et al 2006, cited in Vandereycken 2011: 293). It is evident that these spaces have strong negative effects on patients, so that they inevitably fail in their therapeutic function.

In contrast, the dining room of Palazzo Alberese – a typical sixteenth century villa located in the centre of a small town – is a spacious and bright room with three windows decorated by vividly coloured curtains. At the centre of the room there is a big oval table where up to eight patients can sit; towards the windows at the back of the room there are two square tables, for four patients each; on the opposite side a single table facing the wall is reserved – as a therapist explains to me – for ‘particularly difficult patients’. Patients are assigned a different seat every meal, but always trying to keep a disposition so that the most problematic patients do not influence each other. Walls are full of paintings, drawings and pictures that former patients donated to the centre as a gift when they were discharged. There is also a big yellow cardboard with illustrated rules to be followed during the meals: done by former patients, it essentially lists in a funny and joking manner some typical dysfunctional behaviours to avoid – e.g. ‘Do not break food in tiny pieces’, ‘When you peel the fruit, do not peel the pulp away too’. There is always music being played on a radio/cd player during meals. The only element that feels awkward in such a homey context is the way food is presented, which really makes you think about the infamous nasty food of hospitals. Food in fact comes from a cooperative that provides food for schools, companies, and hospitals, and arrives at the centre already individually packaged in the right portions for each patient. Therefore, what you see on the tables is not plates, but sealed plastic packages. A patient – Maria – admitted that the way food is presented is ‘a bit cold and impersonal’, that ‘a proper plate would feel more convivial and help a bit’, but that the kitchen of the treatment centre does
not meet the sanitary regulations required for preparing warm meals. Here it is evident, as Mol (2011: 475) writes, that ‘taste is not just in the food. The surroundings in which people eat also affect how they appreciate it’, including the efforts that carers put into serving and feeding patients. Staff members know that the food provided is not as good as it could be – on top of being food, which for patients is enough to create anxiety – so they actively try to ‘make it taste better’ (ibid.). In the words of a patient:

_I like the fact that staff members try to lessen the tension by turning the music on, by making jokes and creating some conversation...because many of us find it more difficult if we have to stay in silence just looking at our plate. Because then you experience it as an imposition. Whereas trying to create a more convivial atmosphere...I think it helps (Maria)._ 

Rules about meals tend to be very strict in inpatient facilities. Gremillion’s account of an Eating Disorders treatment centre considered to be at the forefront in the US reports that not finishing one’s prescribed calories for the day meant having to complete it with a nutritional supplement – nutritional supplements are renowned to be disgusting – within an assigned period of time. Failing in this would lead to an ‘NG backup’ – i.e. forced-feeding through a nasogastric tube (Gremillion 2003: 17). The nasogastric tube, inserted through the nose and pushed down to the stomach, physically separates the nutritional qualities of food from its taste: patients can thus be provided with nutrients without tasting the food, which is what affords them a sense of vitality (Mol 2011: 472,478).

At Palazzo Alberese lunch and dinner should theoretically last 45 minutes. However, there is flexibility and they often last for an hour – or even more – because carers are ready to spend all the time needed to help patients who have difficulties and are reluctant to eat. Patients are controlled and sometimes scolded if they display dysfunctional behaviours, but mostly in a gentle and joking way. The rule says that they should finish everything in their plate, but there is room for compromises depending on the patient’s condition, especially the first days of stay, that are the hardest. Here the adoption of an all-round and affectionate care is considered a key element for a successful recovery. One of the educators pointed out that sometimes this means being willing to help certain patients wash their bodies when they take a shower, because they feel such a strong discomfort while they are gaining weight ‘that they cannot even touch themselves’. Another therapist often stressed the fact that the treatment approach succeeds only ‘if we really take care of the girls at 360°, as if they were our own daughters’. She also pointed out that this requires a great effort on the part of the staff, and that after a while it becomes very tiring. Indeed, staff members need to assume ‘diluted roles’ (Deiana 2012: 60), since they have to approach patients alternately as health professionals, monitors while eating, games companions and confidantes.

**Conclusion – and the Way Forward: Looking for the Right Balance between Involvement and Detachment**

It is evident how in the case of Eating Disorders enforcing treatment cannot work. But this does not mean that one should condemn altogether the stubbornness that caretakers put in looking after patients to make sure that they are not abandoned in the name of the holy grail of patient choice. Care for sure means listening to and respecting patients’ will. However, given that for those who live with an Eating Disorder will is complexly entangled with need and with the fear to lose the only thing they feel in control of – namely their body – ‘good care’ here means being able to enact the practical
requirements of care even when the patient, at that very moment, would refuse them. The key issue is the modality in which caregivers do this, the kind of affection, patience, dedication and ‘being present’ that they display: ‘So much depends on those concrete things: the doing, the feeling, the shadings, the symphonic complexity, the inadequacy, the living at every moment and over what can be such a long journey of the incompleteness yet the presence of a caregiver’ (Kleinman 2009: 293). Being ready to stay in the lunch room with a patient for three hours if that is the necessary time for her to finish her meal – and being ready to stay there not only as a watchdog, but also as a friendly hand that supports her and makes her feel safe, that is an example of good care I believe. The problem is that it is extremely difficult to make a patient eat while having at the same time this truly present attitude. Caregivers often have to stand by girls who look desperate in front of 40 grams of pasta with tomato sauce, tears coming out at every spoon they put in their mouth. And yet they need to stay there and make them keep eating. It is a torture – not only for the patients, but also for the caregivers.

From this last point, it is clear that there is a need to investigate more on the way caregivers enact their ‘diluted roles’ (Deiana 2012: 60), especially on what they do to reach the ‘right balance’ between emotional involvement and detachment from patients. Those who work in an inpatient Eating Disorders unit have much more contact with patients than any other kind of professional caretaker. They thus feel more than others the tension that exists ‘between care and work – between the individualized demands of compassion and sympathy and the impersonalized, routine demands of the efficient workplace’ (Brody 1992: 66, cited in Gremillion 2003: 138). A kind of unconditional affection is expected from members of the treatment team, but unlike patients’ natural parents, staff members are required to express this care while they are presiding over treatment practices that often look antithetical to caretaking attitudes. Many staff members express difficulties in enforcing the unit rules while maintaining caretaking roles with patients, as the necessarily ‘harsh’ aspects of their job get in the way of connecting with patients emotionally, and vice versa. The key is to learn ‘to set boundaries appropriately’ and to have ‘some detachment from the behaviour’ (Gremillion 2003: 144,145), something that requires constant exercise:

[When I first started working at Walsh], I used to literally sit in my car and imagine letting go all of the kids, not taking them home with me. It had to be that visual, concrete kind of exercise to set some boundaries….Once, we were having this major thing where all the kids were pushing [the rules at mealtimes] […]. What I chose to do for myself was just imagine I was a clock […] And when the time was over, the meal went away! And it wasn’t personal. It wasn’t me setting a limit… [I did this] because it was getting very frustrating […]. And I needed some kind of distraction for myself, so I wouldn’t get angry, overly rigid, punitive” (Gremillion 2003: 146).

In this account, the risks of emotional involvement with patients are perceived to be both caring too much – i.e. wanting to take patients home – and becoming punitive. Staff members are thus expected to reach for a middle ground: they need to mitigate the potentially overcontrolling and punitive aspects of treatment as well as temptations to engage in excessive forms of maternal caretaking (ibid.). Similarly, at Palazzo Alberese I heard some staff members talking in a critical way both about a colleague who was ‘too emotionally involved’ with one of her patients, and about another one who was too harsh and punitive with non-collaborative patients, especially during meals. They were negatively judging the former for being unable to see that her patient was
‘manipulating’ her in order not to gain weight; and the latter for being unable to recognize that patients’ dysfunctional behaviour was not something personal but part of the illness, and therefore had to be taken ‘with emotional distance’. This was the only way not to feel frustrated and react in a way that would simply harm them.

Staff members can explain very well how maternal attitudes can lead to over-involvement or punitive behaviours towards patients, but not so well what constitutes a good nurturing attitude (Gremillion 2003: 149,150,153). This surely consists in finding some balance between emotional involvement and detachment, but where this balance exactly lies is not clear; what is clear is that reaching it requires time and constant exercise. An ethnography of daily care for patients suffering from Eating Disorders should thus involve storytelling about the activities of healthcare workers – how they perform and experience their caring work, their intentions, their concerns – and about ‘the activities of things’ (Harbers, Mol and Stollmeyer, 2002: 219) mobilized by them – tables, plates, cutlery, tastes, temperatures, textures, music, gazes, jokes – as intended by carers and as experienced by patients. These stories should articulate the situations in which healthcare workers feel they are intruding and crossing the line of enforced treatment, the occasions when there are tensions with patients and within themselves – and should therefore point out the different ways in which ‘the good’ for the patients is sought (ibid.), sometimes reached, and sometimes lost.

References


ARTICLE

CONTROL AND CARE AT THE END OF LIFE:
PERFORMING THE ‘GOOD DEATH’ IN PALLIATIVE CARE, AN IRISH PERSPECTIVE*

BY LUCIANA LOLICH & KATHLEEN LYNCH

Abstract: This paper explores the idea of control, performance and care in palliative care in Ireland in relation to the concept of a ‘good death’. Utilising the concept of the ‘performing self’ (Featherstone, 1991), this analysis of the good death is a first step in attempting to identify inequalities in care and dying. With increased professionalization of death and dying a paradox has emerged, on the one hand there is a redistribution of power and authority that lies with the medical expert, and on the other hand a discourse of patient autonomy and choice is promoted. However patient autonomy and a choice logic ignore the way economic and affective resources, power differences and cultural values mediate the meaning of death, and what is desirable and realisable as a ‘good death’. Choice logic assumes that all patients are independent and autonomous, even at a moment of high vulnerability. Finally, choice logic leaves unspoken the highly gendered assumptions as to who will do palliative care work at home.

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Introduction

The ‘good death’ has always been a fundamental goal in hospice/palliative care (Clark 2002; McNamara 2001). In recent decades there has been a transformation of the original meaning of palliative care¹, marked by an increased medicalisation and secularisation of death and loss (McNamara 2001; Walter, 1994). It is not surprising therefore that many have questioned what constitutes ‘a good death’ in a world that for many is post-religious and medicalised (Clark 2003; McNamara 2004). In thinking about death, many people construct an ideal death – well-known examples include ‘dying in one’s sleep’, dying on the job and ‘dying with one’s boot on’ (McNamara 2001, p. 41). These ideals draw upon representations of good and bad ways of dying and they are found in many cultures (Bradbury 1996, p.84). While these representations may share similar social functions to some extent, their actual foundations and manifestations are quite diverse. The notion of a good death is not new but it has evolved over time. There are many ways of dying and with each way there are multiple meanings of death that are expressed individually and culturally (McNamara 2001). Moreover, perceptions
and social norms about death and dying change over time according to cultural values, beliefs and attitudes (Ariès & Armiño, 1983; Kellehear, 2007). Though death itself may be a predominantly physical or biological event, both death and the process of dying are imbued with social, cultural and political meanings (Cottrell & Duggleby 2016).

The performing self
In current Western societies the conceptualisation of the body imaginary has moved away from the body as susceptible to deterioration to the body as a field of possibilities (Le Breton 1990). The body is a source of pleasure but also a source of pain. On the one hand we have a body that is undermined and made feel inadequate and obsolete by technology and on the other hand, we have the spoiled and worshiped body of consumer culture. Nowadays, the body is presented as a machine that needs looking after in order to optimize its performance (Le Breton, 1995). Today’s narcissism is not about lazing around and chilling out. It is about working on the self through your clothes, your attitude but mostly through your physical appearance and disposition. The relationship we established with our body imaginary is not only particular to a specific historical and cultural context but is also specific to social class (Boltanski, 1975; Le Breton, 1995), gender (Isaksen, 2002) and race. Foucault has shown how the key to disciplinary power is the construction of a micropower, starting from the body as object to be manipulated (Dreyfus, Rabinow, & Foucault, 1983 p. 153). The notion that one has control over her or his life is part of the market logic of responsibilization of individuals. Individuals are responsible for the good performance of their bodies. The performing self controls his or her body through acts of consumption (Featherstone, 1991). Within palliative care the concept of the ‘good death’ implies that the individual, as a performing self, should have control not only over his or her life but also over his/her death. Within consumer culture, patients are asked to become role players and self-consciously monitor their own performance. There is a script to which the terminally ill patient in palliative care should adhere to and failure to do so can lead to being labelled pathological (Zimmermann, 2004) and results in a shameful death (Kellehear 2007). These patients represent ‘failure’ not only for curative medicine but also for hospice, in that they refuse to accept their terminal condition.

Within a culture in which the body is the passport to all that is good in life (Featherstone 1991, p. 186) the body of the terminally ill becomes shameful and problematic. There is a lowering of one’s acceptability as a person, a sense of low self-esteem and even moral failure (Featherstone 1991, p. 186). Within a logic of consumer culture and high performativity it is difficult to provide other than flawed solutions to the problems of ageing and death (Featherstone 1991, p. 186). We argue that consumer culture has penetrated palliative care (Borgstrom 2015) and a partial solution to the problem of death is the empowered patient than through a market logic can exercise choice over death.

The ‘good death’ in palliative care
Control has a critical and complex relationship with the ‘good death’ discourse (Cottrell & Duggleby, 2016). This includes controlling dying activities, controlling the timing and place of death, dying as a form of social control and control of unpleasant and painful physical symptoms. The good death normative can be interpreted as a form of social control and can imply a social class normalisation of death and dying (Conway, 2013). By providing a strong cultural script for the dying, as well as for those who care for the dying, the ‘good death’ directs attitudes
and behaviours and creates a certain socially sanctioned way to die or to care for the dying (Cottrell & Duggleby, 2016, p. 3). Kellehear (2007) discusses our different conceptualisations of death and dying from the Stone Age to contemporary forms of dying. Control is always an important aspect of it, albeit in different forms.

The contemporary good death what Seale (1998) termed ‘the revivalist good death’ arose as a backlash against the medicalised death and was spurred by the hospice movement (Gott, Small, Barnes, Payne, & Seamark, 2008; Seale, 1998; Walters, 2004). The revivalist alternative proposes an elevation of the private experiences of dying and bereavement, so that these are brought into the field of public discussion. Though subtle variations exist, the Western revivalist good death ideal is expressed through the literature as a peaceful and dignified death, free from pain and other distressing physical symptoms. Death is timely. It occurs in old age and follows a predictable course. It occurs at home, with the dying individual surrounded by family members². Furthermore, in a good death the dying individual is aware³ of and accepts their impending death, has made appropriate legal and financial preparations, and ideally, has planned their dying experience through an advance directive (Granda-Cameron & Houldin, 2012; Kehl, 2006). Palliative care plays an important part in this process of the modern ‘planned death’ (Zimmermann 2004 p.1777). In late modernity, a novel discourse of death and dying has surged, the dying patient is encouraged to speak (Armstrong, 1984) and in speaking, engage in the planning of his or her own death (Gillick, 1995).

The current conceptualisation of the good death in palliative care has been subject to ongoing critique in terms of its secularisation, increased medicalization and professionalization (Bradshaw, 1996; Clark, 2002; McNamara, 2004; Zimmermann, 2004). This paper is concerned with the increased medicalization and professionalization of death and dying (Biswas, 1993; Floriani & Schramm, 2012; Kellehear 2007; McNamara, 2001; Weber, 1995). With increased professionalization of death and dying a paradox has emerged, on the one hand there is a redistribution of power and authority that lies with the medical expert, and on the other hand a discourse of patient autonomy and choice is promoted. Because the scope of palliative care includes patients that still have many years left to live and might still be receiving active treatment there is an increased dominance of the doctor in the care of the patients. However, paradoxically at the same time that we see an increased medicalization in palliative care, there is a discourse of patient-centerness, choice and control. The discourse on patient autonomy represents the ideology of the market with a focus on consumer empowerment as a fundamental aspect of a good death (Borgstrom & Walter, 2015; McNamara, 2004; Zimmermann, 2004). The preoccupation with control as a unifying aspect of the ‘good death’ speaks to the perceived importance of market and social values of autonomy, freedom and choice (Cottrell & Duggleby, 2016). While there is nothing inherently problematic with the idea of choice, (it is a very important principle that needs respecting) the problem arises when we assume that people who can fully exercise choice are the norm (Kittay, 1999), including in palliative care. Furthermore, in some occasions choice is not claimed by citizens, but offered by those in power, citizens are required to make choices, even if their choice is not to choose (Armstrong 1984). The person who is dying is to be empowered to be in control even if they do not wish this. Consumer choice, has now become essential to palliative care and it is seen as a way to regain control on an increasing medicalization of death. The patient becomes the
performing self, performing the role of the empowered, active patient, who is in control and able to exercise choice.

Illustrating choice in Ireland: Home Death

A recent IHF (2014) report states that the ability to die at home is a fundamental part of a good death for people in Ireland. Within the role of the performing self, there is a prescription that the correct way to die is a home-death. There is an international move to reduce hospital stays, to increase community support on the grounds of reducing hospital-acquired infection, healthcare costs⁴ and to more closely meet patient and family choice. It is in this context that one of the fundamental norms surrounding the concept of a good death in Ireland is that the patient should be able to choose their place of death⁵⁶. However, constructing choice as a fundamental aspect of a good death demonstrates the influence of consumerist ideologies on palliative care and it assumes that the place, and even manner of death and dying, is largely a matter of volition (Pollock, 2015).

In a research conducted by the IHF, nearly three out of four respondents – 74% of the total – said that they would like to die at home (McKeown et al., 2015). However, several papers have raised issues in terms of the methodology of this type of study. Most studies are cross-sectional and taken at times in life when death may not be imminent. Longitudinal studies show however that choices change over time, shifting slightly from home to hospital death (Thomas, Morris, & Clark, 2004; Townsend et al., 1990). Also, it has been suggested that when hospices are brought into the equation, the perspective may change. A home care/death may not always be a positive judgement based on the ‘intrinsic’ qualities of a home environment. The decision may be driven by negative impressions of other care environments (Gomes & Higginson 2004). It has also been pointed out that a substantial number of people do not specify a preference (van der Heide, de Vogel-Voogt, Visser, van der Rijt, & van der Maas, 2007) and there is rarely an option for ‘it depends’ or ‘does not matter’ (Stajduhar, Allan, Cohen, & Heyland, 2008). Furthermore, when three fundamental outcomes of a good death are examined: pain, pace and grief, findings were inconsistent in terms of home being the best place to die for the patient and his or her relatives (Escobar Pinzón et al., 2011; Parkes, 1978; Wright et al., 2010).

Constraints on choice – equality considerations

Not being able to control and choose in death is seen as a failure in and outside the hospitals. Making control and therefore choice an overriding quality indicator has serious implications for an equal society as the degree to which a terminally ill person has control or is able to actively choose is linked to age (Rinaldi & Kearl, 1990), patient residence (Irish Hospice Foundation 2012) and the degree to which hospital/hospice staff set limits upon their own involvement with patients and families (Mesler, 1994). And, as McNamara (2001) has pointed out, we must also be aware of the terminally ill person’s social location within the broader society. Ethnicity, educational background, occupational status, gender and the kinds of social supports terminally ill people receive all contribute to their social location and must be understood in the light of entrenched social inequalities. Death is not the great leveller and we die much as we have lived (McNamara 2001 p. 61). Those who have lived a life of disadvantage tend to die in disadvantage circumstances (Kellehear 1994). They may have access to medical care, but we must also ask to what extent people are able
to understand and utilise the services that are available.

To manage dying and death, one needs resources, not only to manage the events themselves but also to preclude an untimely, or unmanaged death. Historically, there has been a perception that palliative care services are for white middle class people (Kellehear 2007; Ling & O’Sioráin, 2005) and there has been an acknowledgment that minorities like Travellers, people with life-limiting conditions other than cancer, children and people living in certain parts of Ireland are precluded from accessing specialist palliative care (Irish Hospice Foundation 2012 p. 7; McQuillan & Van Doorslaer, 2007; Sleeman, Davies, Verne, Gao, & Higginson, 2015).

The capacity to exercise control and therefore choice over one’s life and death is linked to wider social systems, this is to say, to economic, political, affective and cultural systems (Baker, Lynch, Cantillon, & Walsh, 2004). We argue that the conceptualisation of the empowered patient is an extension of the performing self who needs to retain some control in the face of a failing body and a narrowing of choices in the face of the inevitability of death. While attempting to control death is part of the exercise of control on life itself, we are suggesting that there is a growing emphasis on control and choice in a neoliberal age where choice and control, especially in relation to the body, are increasingly defined as virtues in and of themselves. When awareness of dying and support for the dying are rare, the performing self is expected to exercise control over the manner of the dying, even if this control is only illusionary or only a few can choose.

Focusing on place of death as a quality indicator (QI) has limitations therefore as it ignores patients’ relationality and distracts attention from the experience of dying for patients and their families (Wood & Salter 2013). At the end of life, people repeatedly express a desire not to impose a burden on their families (Leadbeater & Garber 2010; Wood & Salter 2013; Gott, Small, Barnes, Payne & Seamark 2008; Thomas, Morris & Clark 2004). Their death is mediated through their relationality not as an autonomous consumer of palliative care or hospital services. And a perceived advantage of the hospital is that professional input can relieve the strain on carers and families (Thomas, Morris & Clark 2004; Broom & Kirby 2013; Seymour, Payne, Chapman & Holloway 2007). Evidence suggests that place of death is not the over-riding priority therefore. Some studies, including Irish studies (IHF 2014), have shown that when people are asked what is important to them in case of terminal illness; control of symptoms especially pain, and being accompanied by loved ones are more important (Waghorn, Young & Davies 2011; Muragh, Bausewein & Petkoava 2012).

It is important to consider how patients make choices as relational selves therefore. They do not choose in isolation from their family, their culture and values. They are often struggling to make these choices in the way health policy demands of them (Borgstrom & Walter, 2015) even if it is not of their own choosing.

**Conclusion**

This paper argues that the contemporary concept of a good death in palliative care reflects a growing market ideology that prioritizes control and choice over compassion and care. We argue that consumer culture has penetrated palliative care and a partial solution to the problem of death is the empowered patient that through a market logic can exercise choice over death. It ignores the way economic resources, affective resources, power differences and cultural values also mediate the meaning of death and what type of good death is desired and is realisable. Also it assumes that patients are independent and autonomous being, even at a moment in life of high vulnerability.
The notion of individual control, through the exercising of choice, is fundamental to the market ideology that has been normalised in palliative care thinking in many Anglophone countries in recent years (Borgstrom & Walter, 2015). Grounded in system of beliefs that glorifies independence and denigrates dependency (Kittay, 1999), it assumes that the idealised adult is autonomous and in control over their bodies and the end of life itself. It promotes an idealised view of the ‘good death’ as one in which the person exercises control and choice over the dying process.

The person who is dying is subject to rule of performativity in relation to the ‘good death’. They are expected to organise the most disorganised part of life, the stage pre-death. The norms governing this stage of life’s performance are increasingly secularised, technicised and governed by professional (especially medical) logics more so than on compassion and care for the person in palliative care. Moreover, the concept of the ‘good death’ is based on assumptions about end-of-life care that disregards the ways in which existing inequalities in economic, political, cultural and affective relations create an ‘illusion’ of choice for many: they have neither the economic resources or affective supports to make particular choices. Nor are certain choices in accord with their cultural values and beliefs. Thus the dominant narrative in Ireland that a good death is one where you ‘die in your own bed’ at home is in need of problematisation not least as it assumes that families have the resources and affective capacity to care for a person at the end of life at home. Finally, choice logic leaves unspoken the highly gendered assumptions as to who will do informal (unpaid) and formal (paid) palliative care work at home, when dying at home is made a priority ‘choice’.

References


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Notes

1 Palliative care is the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement (DoHC, 2001, p. 20). For an extensive analysis on the conflicting ideas of what exactly constitutes palliative care please see Pastrana, Jünger, Ostgathe, Elsner, and Radbruch (2008).

2 This last aspect is an essential characteristic of the definition of the ‘good death’ in Ireland. In the Irish Hospice Foundation report *Enabling more people to Die at Home* it states that ‘One of those deepest wishes is the hope for a ‘good death’. While interpretations of a ‘good death’ may vary, for many Irish people the wish to die at home is a fundamental part of it (Irish Hospice Foundation, 2014 p. 4).

3 In Ireland there is still an implication in palliative care reports that the subject’s awareness of impeding death can lead to a good death. For example by asking a rapid discharge form hospital to be able to die at home (Health Service Executive 2013; Irish Hospice Foundation, 2014 p. 8).

4 The need to reduce costs is an important incentive for reducing deaths in hospitals (IHF 2014, Leadbeater & Garber 2010, Wood & Salter 2013; Hatzziandreu, Archontakis & Daly 2008).

5 Place of death has been proposed as a quality indicator (QI) for End Of Life Care (EOLC) and it is an attempt to provide simple metrics to measure success in meeting the preference of more people to be cared for and die in a home setting (IHF 2014, p. 3).

6 Although the IHF (2014) suggest that choice and control over place of death are fundamental aspects of a good death, in an earlier study commissioned by the IHF (Weafer & Associates, 2004), examining Irish attitudes to death, dying and bereavement, home as a place of death was not mention as an important factor in a good death.

7 The IHF (2014) recognises that where we die is not just matter of personal preference and it depends on
what supports are in place to allow us to die at home. Dying at home might not be a consistent experience for all people, the quality of the home and community support varies and this might affect the quality of ‘a good death’ and therefore not in the best interests of the patient. These factors include the presence of a carer, the nature of the illness itself and the symptoms associated with it, socio-economic and demographic status and the availability of local services.
I met with professor Arthur Kleinman a day after his keynote speech at the 2016 AAI conference in Maynooth. The talk he delivered was a moving account of the politics and morality of care and suffering. But the power of his speech came not only from the insightful theoretical approach, but first and foremost from sharing a very personal experience of care-giving to his wife of 45 years, Joan, who was diagnosed with Alzheimer’s disease in 2003, and whom Kleinman was taking care until her death in 2011. So when we met for this interview, I somehow expected a conversation which would continue in a similar vein, and would follow up on the topics raised the day before. But paradoxically, in this small Maynooth cafe, the intimate atmosphere of the yesterday’s lecture hall was nowhere to be found. But even though our talk had a very different ambience, it revealed a great dedication of Professor Kleinman to anthropology. Without much of ado he directed our interview to the most current issues in academia. Echoing the conversations that are happening in most universities in the world, including Maynooth, where curriculum reform is being introduced, Professor Kleinman noted that we live in a time, when universally the whole academic world is changing: research universities are moving away from a balanced model combining science, humanities and social sciences to a model led by applied science. That worldwide emphasis on applied science raises a question about the purpose of the humanities and social sciences, and what is their role in the education of students generally, and what role do their fields have. Eventually what happens is the contraction of humanities and social sciences, which has very substantial significance for anthropology.

E. Drążkiewicz: So what is the future of Anthropology in that context?

A. Kleinman: It’s pretty clear that one of the domains in anthropology and sociology that will be supported in the future is going to be that aspect, that has to do with real world problems and real world solutions. Within that domain what will also be prioritised will be, what we in the USA call area and global studies. Global studies are going to be dominant in the Universities in future, and the issues there which are going to be dominant will be global health, global environment, global trade and finance, global energy, global aspects of social and health inequality. The extent, to which anthropology and sociology will engage in these areas, will be the extent to which they will be supported. And if they don't they will have trouble surviving.
[This assessment of the future trajectory of anthropology comes from the reflection on Kleinman’s own field of study.] 

The area I do, medical anthropology and the related area, the anthropology of science are very popular in the United States and in much of the world because it is one of the ways in which anthropology makes a profound contribution to the real world problems. This is reflected in the career paths of those I have trained in medical anthropology. Majority of them are teaching at the universities, but a lot of my students went outside of academia in a way they might not have in the past. So for example, if you look at my students from Harvard MD – PhD programme, where people get medical degree and PhD in social anthropology, you will see that one of them is Jim Yong Kim, the president of World Bank, the other one Paul Farmer is probably the main figure in global health. Another one, Matthew T. McGuire, holds a strong position in the Obama Administration. So this speaks to our condition and our future. And the reason I am saying this is that 50 years from now if anthropology makes no significant contribution in improving people’s lives, and improving society, there will be no anthropology, in my view.

ED: So what is your suggestion, how can anthropologists engage with the world, get involved?

AK: Anthropologist simply will have to become more active, to become more successful. Political science is a much larger field than anthropology. They work in the field and they work collaboratively in the field. Development economists, they also work in the field, and also in collaboration. Sociologists work also in a very non-laboratory way, in a field but they collaborate.

ED: So why is there no such thing in anthropology?

AK: Because anthropology, in this regard, is closer to humanities where a dominant model is a sole author working on things by herself. But in literature and in history that is beginning to change and it will have to change in anthropology as well. I am of course not against you writing your own book on your field research. But in addition to that you have to do other things. Attend workshops, conferences where your work is connected to political science they all are becoming increasingly collaborative enterprises, where books are written by several people, articles co-authored.
other work. You have to engage global studies in your area in some way. When Raymond Firth won an award from the Royal Anthropological Institute in the 1980s, and we actually were awarded medals at the same time, in his speech he said that anthropology strength was in the big questions it asked. Its weaknesses were its methods. It’s a wonderful method to illustrate very important ideas, to make connections with theory. But in my view, the importance of theory is not only to guide research, but also social policy. And this dimension of anthropology has not been developed substantially enough: a connection of anthropology to policy. This is what Paul Farmer, Jim Kim, Matthew Basilico and I were trying to achieve in our book “Reimagining Global Health”. This book came out from a course that we teach at Harvard. What it does, it teaches global health through social theory. We take key theories of Weber, Foucault, Bourdieu, and many others and use them to develop health programme interventions. We show how central medical anthropology is, both theoretically and in terms of ethnographic research, to the implementation of those programmes. I strongly believe that the main purpose of anthropology and sociology is to improve people lives and to contribute to social reform. I think now we finally have recognised that cultural critique is crucial but insufficient. The problem with anthropology, I think, is that we haven’t moved very far beyond cultural critique, and forgot that social betterment is the founding idea of social sciences. If you look at great liberal thinkers such as Adam Smith, John Stuart Mill, John Locke and many others, you will see that they believed that the main purpose of systematic social inquiry was to improve society and social life. But also Max Weber, C Wright Mills, Hannah Arendt, Jane Addams, the entire Boasian school of anthropology, Herskovits and many others who were internal critics of sociology, they also believe that the most important questions are those of how to improve the society. Hannah Arendt is a great example here: she is a great political theorist but also very influential outside of academia. She said that we have more or less forgotten the social question in social science. The problem is that most of the questions are articulated either on an individual level, or on such a massive macro level that almost nothing can be done. So what is important is to reconfigure the questions as social problems and look for potential social solutions to those problems. For instance, if you think of substance abuse today, or the depression and anxiety that are affecting refugees and migrants and people who lost jobs. Those are very important issues that are bound up, and have their sources in structural violence or neoliberal political economy, or other things. And it is important to note that. But there are things that can be done. These might include the reforming of the economy, but also there things that can be done on the ground to improve the quality of lives of these people.

ED: Can you think of examples, from your own work of such engaged work, of successful contribution to the social change?

AK: My own career is organized around China studies. I was the first foreigner, the first non-Chinese who systematically studied the survivors of the horrific Chinese Cultural Revolution. I did that early on in 1978, 1980. In fact my research is probably the first research on that topic. I showed what effects the revolution had on intellectuals, on workers, on cadres and how those traumatic effects were embodied. Of course, back then the collective complains, could not be voiced openly or you went to prison. However they could be voiced in bodily terms. I showed how three bodily metaphors were in fact pointing to the fact that people were exhausted, injured and disoriented from the political
campaigns that they have gone through. I also showed that people who came out of these public campaigns with serious depression or anxiety could be treated, even though these were conditions which were unrecognised, at that time, in the Chinese society. But I think the best help that I gave is illustrated in the letter from one of the people I interviewed in the 1990s who was a leading cadre in central China, and who was terribly abused during Cultural Revolution for over a decade. He wrote me a letter out of the blue, as I lost touch with him. He wrote through his son, who is a professor in one of the universities in California and tracked me down. And in this remarkable letter, in Chinese, he said: “you know, you were the first person to listen to me, whom I was able to tell my story to, and that was enormously important to me, and it kept me going for that time”. And I think that was very important in that research, and in any research: to allow people to tell their stories. I believe this is a very important aspect of anthropology: the kind of personal narratives that it can solicit. I developed an entire technique for doctors and nurses in medicine to do that kind of thing. But also anyone who is doing research today with people who have been seriously injured in a natural or social or political catastrophe, anyone doing that can benefit from it, as their research goal should also be contributing to help that person. You can't just do research, or else it becomes voyeuristic and it can injure people. My research method is a way to get deep information about people’s experiences, but at the same time to support who they are. I believe that this is the fundamental moral basis for social research. I see that many anthropologists don’t do that, but I would say that this will be changing now because ethical review committees will not approve in future any ethnographic research, unless there is some evidence, that attention is being taken that it doesn’t hurt people, doesn’t injure them and that it does or intends to do something positive for people. This is a social care approach to research.

Of course, in applying this method, in some ways I am advantaged because I am both anthropologist and psychiatrist. But even if you look at the origins of anthropology, especially in UK where many of the members of the Torres Straits expedition were doctors or psychiatrists, you will realise that there are many dimensions of clinical medicine and anthropology that have similarities. For me, one of the most important ones is intensive involvement with people, an engagement with the problems people experience. Of course, I am not asking that anthropologists become practitioners of some sort of therapeutic art. I am simply saying that in doing social science, in doing ethnographic research, in making comparisons, in using social theory, they also have to think about what are the implications of this for social policies and programmes. We actually allowed sociologists to dominate that area. I don’t think that is going to happen anymore. Otherwise there will be no anthropology anymore.

ED: But there are many people in anthropology who are actually against political engagement, and for whom a ‘real anthropology’ is the one concerned with tribes in Amazon, rather than let’s say development or organisations, or studies of Western societies. Why do you think is that?

AK: First of all in my country, in US very few anthropologists are studying tribes in Amazon. We are studying large scale societies, we are doing anthropology of the US, or in my case of China, so just in doing that we are asking a different set of questions. But even in the case of those who do the anthropology of small scale pre-literate societies, there is that dimension of
the work, which they never write about, which is that you can’t be in a society where there is a very high mortality rate, where people are sick all the time without contributing. So, the same medicine that they brought for themselves they share with others, or they drive people if they have a car, so they try to contribute in some way to the society that they are in. From an ethical standpoint, if you don’t do that, you are occupying untenable ground. You are just preying on people. You are observing and preying on them. And who reads most anthropological monographs anyway? Do the people from whom the knowledge was extracted read them? Of course not! So you can say that a certain part of anthropology has been engaged in knowledge extraction. Not dissimilar to the extraction of oil, minerals, of wealth that is taking place under colonialism and neo-colonialism. My point is that it is as untenable to extract knowledge as it is to extract minerals without somehow giving back.

But let me just say that I also don’t except the idea that if you engage with the world, for instance through medical anthropology, that you can’t be theoretically sophisticated or write on the highest level. I would say that ethnographies in medical anthropology are some of the best ethnographies ever written, that social theory done in medical anthropology is as rigorous as any other done in any other way. I don’t see medical anthropology, very frankly, as an applied field. I believe this is theoretically sophisticated field, which, in my view, represents the best of social and cultural anthropology. That is how I feel.

**AK:** Well this can be done by beginning to write things that can be read by policy makers, and here I think we have a long way to go. But speaking from my own experience, this April I am doing something in the policy domain that I have tried to do a couple of times. In 1995 at the UN in New York I led a project for World Mental Health. That made a first report on the status of mental problems in the world, and the way they were being dealt with or not dealt with. And Boutros Boutros-Ghali, who was Secretary-General of the United Nations at that time, took it on board and it had some effects in helping to build global mental health as a field. But this April [2016] with the head of the World Bank Jim Yong Kim, and with Margaret Chan, the Head of the World Health Organisation, I am co-chairing a programme, aimed at the Finance Ministers of the world, on depression and anxiety. These are the two mental illnesses that I spent my career working on and relating them to social development, to humanitarian problems. I have always worked on implementing effective interventions to them. And the reason the Bank is interested in it, is that we have a lot of evidence to demonstrate indirect economic costs of these problems. This means in a sense that depression amongst poor people, in settings in which there are limited job opportunities and resources, there depression is the major barrier for people to be able to find work and to improve their lives. When you go to the area that is poor, of course not everyone has depression, not everybody has anxiety, but if you can assist those who have it, if you can help them in finding work and having more adequate success in life, I think this is a real accomplishment, and we are going to work on that. For the first time Finance Ministers will begin to take that seriously and began to invest in the programmes in this area. Let me just say that: it is easy to stand back and say: “oh but you are not removing all the poverty, you are not changing societies. We should wait for the revolution to happen, for when

**ED:** But what would be your suggestion on engaging with elites, with policymakers, how this can be achieved?
the world changes, and when we get rid of the neo-liberal economic system, then things will get better”. Voltaire said exaggeration doesn’t count. Those utopian ideas are foolish, not just foolish, they are dangerous and they are held by social scientists who hold the position that I find morally untenably: they believe that they are ethically on the higher level, that they can look down from a mountain top at people struggling in the world, and treat them as if they were ants. And then they speak how the ants were organised, and how they failed. But the truth is that these researchers are part of the same universal experience that all of us have. The anthropologist is not better and no worse than other people. Anthropological knowledge is embedded in the real life experiences of people. That is the basis of my work, and this idea became central to a book that I co-edited with Veena Das, Bhrigu Singh and Michael Jackson “The Ground Between: Anthropologists Engage Philosophy”. In this book you will see that my theories have been organised around this idea that we are all in this together, that the knowledge comes from experience and goes back to experience and informs it. My whole life I have been enormously influenced by William James, Jane Addams, and also John Dewey - American pragmatists. And they all argued that all knowledge, all social knowledge comes from experience. If you are going to understand that, this engaging with experience, you have to dive deeply into it. But you also have to bring back this knowledge, back to experience in order to help people, to improve the social world.