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MSo

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CONTENTS

Editorial

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Welcome to this issue of Medical Sociology online, the first of three planned for 2013. The content in this issue is wide-ranging and includes peer-reviewed articles, abstracts of recently awarded PhDs, a reader's digest and information about the MSo/MSN archive.

The archive is an exciting legacy initiative recently begun under the stewardship of the MSo editorial team and undertaken by the MSo administrator. In celebration of the archive and as a mark of respect to one of the founders of the Med Soc group, we reproduce a paper by Mildred Blaxter, which still has as much currency today as it did when it was originally published in 1996.

The first peer-reviewed article by Thonnes and Jakoby entitled 'Where people die: a critical review' discusses how the place of death reflects social patterns and is influenced by factors such as gender, socio-economic status and features of locality across the rural/urban spectrum. The focus is on western societies and in this context the authors' findings challenge the classic institutionalisation of dying thesis.

The next article by Dumbili has a very different context and explores changing patterns of alcohol consumption in Nigeria, drawing out how the decline of traditional value systems is contributing to an increase in alcohol consumption with attendant negative social consequences.

The subject of Sasha Scambler's commentary is a critique of the cochlear implant debate from the perspective of hearing parents of deaf children. Previously hearing parents have been largely missing from the literature on both sides of the cochlear implant debate and this thought-provoking article seeks to redress the balance.

Since our last issue in November 2012 we have received a number of abstracts of recently awarded PhDs relevant to our field and nine appear in this issue. We offer our congratulations on their successful completion and look forward to including more abstracts in forthcoming issues.

We have three book reviews in the current issue; we would like to have more of these so if you have read a recently published book, or indeed an interesting article, that is relevant to our field, please consider submitting a short review for Medical Sociology online.

Concluding this issue is a new feature that we hope will be of value to our readers. Rather than a book review, Rosaline Barbour provides a digest of current articles recently published on Online First. These articles will shortly be published in a range of journals of relevance to the medical sociology community.

Finally, we would like to express our sincere thanks to colleagues across the globe who volunteered their time and expertise to peer review articles in 2012.

Looking Back: Extending the MedSoc Archive

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Much has changed since 1973. It was the year in which Britain, Ireland and Denmark joined the European Economic Community; Nixon was in his 2nd term as US President and Edward Heath was Prime Minister in the UK; the war in Vietnam finally ended; the first cellular 'phone call was made in the USA; in Britain The Open University awarded its first degrees; The Princess Anne married Captain Mark Phillips; The Pink Floyd released The Dark Side of the Moon LP; and the UK sitcom 'Last of the Summer Wine' (*LotSW*) started its record breaking 37 year run on the BBC.

Of considerably more importance, and out lasting *LotSW*, 1973 was also the year in which the first issue of the Medical Sociology Newsletter was published.

The Medical Sociology Group at the British Sociological Association had been in existence for a little over 3 years and that year, according to the history on the BSA website (*http://bit.ly/XWX8SQ*), the committee decided that "…more effective channels of communication are sought and so the first medical sociology newsletter is born…". It was apparently printed at a cost of £3.50 (over £36.00 in todays money!) and posted out to 450 individuals.

The early newsletters were published 2 or 3 times a year. They were typewritten and consisted of letters to the editor, commentaries on current issues, abstracts form journal articles, notices of up-coming events and conferences, book reviews and, perhaps surprisingly, advertisements, usually from publishers about forthcoming books.

By 1977 the name on the cover had been shortened to 'Med Soc News' (although it continued to use its formal name inside) and it continued to be printed and mailed out under the title of MSN until 2005 when it metamorphosed in to MedSoc online, the web based publication which continues to this day.

As I said in my opening remark, much has changed in the last 40 years and the transition from the Medical Sociology Newsletter to MedSoc online (MSo) is just one more way in which our world has changed. Through the Internet and the World Wide Web, MSo, as an open access journal, is theoretically available to everyone and is visited by over 10,000 people each year - a huge increase over the original mailing list - but equally there are functions of the first MSN which MSo no longer provides in the 21st Century.

Email and mailing lists (such as the MedSoc JISCmail list) have taken the place of event and conference announcements in a thrice-yearly newsletter. Likewise, publishers make good use of email lists and their own websites to publicise forthcoming books, rather than take advertising space in a printed publication. Letters pages have been replaced by 'tweets' and 'blogs'; abstracts from papers in learned journals (which are interestingly, mostly still printed) can normally be accessed electronically through institutional subscriptions.

Of course MSo has evolved too. It is now a peer-reviewed Journal focusing on publishing the work of early career researchers but it does continue the tradition of publishing plenaries and reports from the MedSoc Group Annual Conference. It also continues to publish abstracts

from recently awarded PhD's, bringing the latest graduates to the community to everyone's attention. Book reviews too continue to be an important feature of the content in each issue.

What, you may ask, is the point of this retrospective? Well, the answer is that we have been very fortunate to obtain, courtesy of Professor Barbara Harrison at the University of East London, an almost complete collection of back issues of MSN covering some 27 years, from the Autumn of 1974 up to the end of 2001, by which time the newsletter was also being made available electronically.

Whilst much of what is contained within this archive is in some ways irrelevant today - conference and meeting announcements, books long since elevated to seminal status - the rest has been lost to all but the wise few who kept their issues of MSN carefully filed, as Professor Harrison did. There is much contained within them which makes fascinating reading for those who have been involved over the years and must be of interest to todays students.

With this in mind, the MSo Editorial team have decided to embark on the task of scanning and digitising each and every one of the issues in Professor Harrison's collection and to make them available on the MSo website. It is hoped that this addition to the archive will, like the electronically published versions, be fully searchable. This is very much a manual task, and will take some time, but we hope that much of it will be completed by the time of our next issue at the end of June 2013.

I did say that Professor Harrison's collection was '*almost complete*'. There are still some missing issues and we would appeal to any other member of the MedSoc community who also kept their copies of MSN safely, to help us by looking to see if they have any of them which we might borrow. Details of those we are missing are listed below.

Finally, as a taste of what will soon be available online, we are re-publishing an article by the late Mildred Blaxter 'Criteria For The Evaluation Of Qualitative Research Papers' which originally appeared in Volume 22 Issue 1 back in 1996. Despite it being some 17 years since its publication, both the BSA and MSo are regularly asked for copies of this article

Missing Issues

1.1			**17.1**	1991?
1.2			**17.2**	1992?
1.3			**17.3**	1992?
2.2			**19.2**	1994?
3.3	Was it ever published?		**19.3**	1994?
5.2	Late 1978?		**23.3**	August 1997?
7.3	Late 1980?		**25.3**	September 1999?
11.2	Early 1985?		**29.1**	Spring 2003?

If you have a copy of any of these issues and would be happy for us to add it to the archive, please contact *charlie@medicalsociologyonline.org*.

Criteria For The Evaluation Of Qualitative Research Papers

Mildred Blaxter

At the 1995 Conference of the Medical Sociology Group at York a Workshop was held at which a preliminary draft outline of a document for Journal editors was offered for discussion. It was felt that medically-oriented journals and funders are expressing themselves as open to qualitative research nowadays, and had expressed a desire for some helpful document about how to judge it.

Subsequently, some 30 people took part in a revision of the draft document, and this was discussed at a Workshop at the 1996 Conference in Edinburgh.

It was generally agreed that different documents might be appropriate for editors/referees and for grant-giving bodies, and that the present criteria would be specifically for papers rather than research proposals. It was essential, it was thought, that such a document should be short - preferably, not more than two printed pages. The emphasis should be on demonstrating that methods with rigour and sophistication have developed in qualitative research, and that there is some consensus on how it should be evaluated. It should be made clear that

- the criteria offered are not exhaustive, but simply a set of guidelines
- they might not all apply to all qualitative research
- the choice of appropriate referees is crucial.

The Suggestion was originally made that a list of potential referees for qualitative work might be compiled. In the end, however, it was decided that this was impractical.

At the 1996 Conference the following formulation of the Guidelines was approved to go forward to the Medical Sociology Group Committee as an agreed document which they might endorse and promulgate.

Criteria For The Evaluation Of Qualitative Research Papers

1. Are the methods of the research appropriate to the nature of the question being asked?

   • i.e. does the research seek to understand processes or structures, or illuminate subjective experiences or meanings?
   • Are the categories or groups being examined of a type which cannot be preselected, or the possible outcomes cannot be specified in advance?
   • Could a quantitative approach haw addressed the issue better?

2. Is the connection to an existing body of knowledge or theory clear?

   • i.e. is there adequate reference to the literature?
   • Does the work cohere with, or critically address, existing theory?

METHODS

3. Are there clear accounts of the criteria used for the selection of subjects for study, and of the data collection and analysis?

4. Is the selection of cases or participants theoretically justified?

   • The unit of research may be people, or events, institutions, samples of natural behaviour, conversations, written material, etc. in any case, while random sampling may not be appropriate, is it nevertheless clear what population the sample refers to?
   • Is consideration given to whether the units chosen were unusual in some important way?

5. Does the sensitivity of the methods match the needs of the research questions?

   • Does the method accept the implications of an approach which respects the perceptions of those being studied?
   • To what extent are any definitions or agendas taken for granted, rather than being critically examined or left open?
   • Are the limitations of any structured interview method considered?

6. Has the relationship between fieldworkers and subjects been considered, and is there evidence about the research was presented and explained to its subjects?

   • If more than one worker was involved, has comparability been considered?
   • Is there evidence about how the subjects perceived the research?
   • Is there evidence about how any group processes were conducted?

7. Was the data-collection and record keeping systematic?

   • e.g. were careful records kept?
   • Is the evidence available for independent examination?
   • Were full records or transcripts of conversations used if appropriate?

ANALYSIS

8. Is reference made to accepted procedures for analysis?

   • Is it clear how the analysis is done? (Detailed repetition of how to perform standard procedures ought not to be expected)
   • Has its reliability been considered, ideally by independent repetition?

9. How systematic is the analysis?

   • What steps were taken to guard against selectivity in the use of data?

- In research with individuals, is it clear that there has not been selection of some cases and ignoring of less-interesting ones? In group research, are all categories of opinion taken into account?

10. Is there adequate discussion of how themes, concepts and categories were derived from the data?

- It is sometimes inevitable that externally-given or predetermined descriptive categories are used, but have they been examined for their real meaning or any possible ambiguities?

11. Is there adequate discussion of the evidence both for and against the researcher's arguments?

- Is negative data given? Has there been any search for cases which might refute the conclusions?

12. Have measures been taken to test the validity of the findings?

- Far instance, have methods such as feeding them back to the respondents, triangulation, or procedures such as grounded theory been used?

13. Have any steps been taken to see whether the analysis would be comprehensible to the participants, if this is possible and relevant?

- Has the meaning of their accounts been explored with respondents? Have apparent anomalies and contradictions been discussed with them, rather than assumptions being made?

PRESENTATION

14. Is the research clearly contextualised?

- Is all the relevant information about the setting and subjects supplied?
- Are the cases or variables which are being studied integrated in their social context, rather than being abstracted or decontexualised?

15. Are the data presented systematically?

- Are quotations, fieldnotes, etc. identified in a way which enables the reader to judge the range of evidence being used?

16. Is a clear distinction made between the data and its interpretation?

- Do the conclusions follow from the data? (It should be noted that the phases of research - data collection, analysis, discussion - are not usually separate and papers do not necessarily follow the quantitative pattern of methods, results, discussion.) "

17. Is sufficient of the original evidence presented to satisfy the reader of the relationship between the evidence and the conclusions?

- Though the presentation of discursive data is always going to require more space than numerical data, is the paper as concise as possible?

18. Is the author's own position clearly stated?

- Is the researcher's perspective described?
- Has the researcher examined their own role, possible bias, and influence on the research?

19. Are the results credible and appropriate?

- Do they address the research question(s)?
- Are they plausible and coherent?
- Are they important, either theoretically or practically, or trivial?

ETHICS

20. Have ethical issues been adequately considered?

- Is the issue of confidentiality (often particularly difficult in qualitative work) been adequately dealt with?
- Have the consequences of the research - including establishing relationships with the subjects, raising expectations, changing behaviour, etc. - been considered?

Where People Die. A Critical Review

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ABSTRACT

There is a great discrepancy in society between the number of people that prefer to die within their home and the number of cases where this wish actually becomes reality. It is generally assumed that the most frequent place of death in Western societies is not the home but an institution, such as a hospital or nursing home. But what is the actual distribution of places of death? Contemporary discourse on the institutionalisation of dying is subjected to critical scrutiny in light of empirical data. Our review shows that places of death are not distributed at random but reflect social patterns. Socio-demographic relationships involve factors such as gender, socio-economic status, or the degree of urbanisation. Moreover, the fairly high and, over many years, constant percentage of people dying at home ranging between 20 to 30 percent additionally casts doubt on the classic institutionalisation of dying thesis.

Keywords: place of death; dying; institutionalisation; death; end-of-life research

INTRODUCTION

Due to the social significance and embeddedness of attitudes and actions that go along with the process of dying, dying not only constitutes a primarily psychological or medical but also a social reality. To the extent that scientific research has given attention to places of death, it has been concerned with issues relating to the degree of institutionalisation of dying in modern society. Historically, in Western societies, dying has occurred at home (Ariès 2005). There is general agreement that the process of dying and the people involved therein have shifted from the personal privacy of the home to the professional enclaves of hospitals and nursing homes in the past sixty years (Elias 2002). The argument suggests that dying now increasingly occurs in medical institutions, such as the hospital (see Howarth 2007: 33). The idea of a sequestration of death refers to the general assumption that the majority of people now die in institutions, away from the public gaze (see Howarth 2007: 24). Notions of hospitalisation or institutionalisation in discourses on the place of death stand for the banishment of death from everyday life (Nassehi and Weber 1989; Schmied 1985). The concept of medicalisation suggests that dying has been located within the domain of medical science (Howarth 2007). Death in the hospital is associated with a new "style of dying" (Ariès 2005: 751). The term "social isolation" is frequently used in this context. It signifies that because of the degree to which dying is institutionalised, the dying person is left to die on his or her own since the process of dying by necessity implies that the person must withdraw from social life.

In the following section, the various perspectives and assumptions about places of death outlined above will be compared with the image of dying reflected in various empirical studies on places of death. Contemporary discourse on the institutionalisation of dying is subjected to critical scrutiny. The literature review is based on the distribution of people dying in hospitals, retirement or nursing homes, hospices, or at home. In addition, other factors

determining places of death, such as medical, structural, socio-demographic, and individual factors, will be summarised.

WHERE DO PEOPLE DIE?

There is a great discrepancy in society between the number of people that prefer to die within their home and the number of cases where this wish actually becomes reality. Studies reveal that the large majority of people asked about their preferences wish to die at home and not in an institution. Studies show that this holds true for 50 to 90 percent of those asked about their preferences (Bell et al. 2010; Thorpe 1993). According to a survey conducted within the context of Switzerland's National Strategy for Palliative Care, 73 percent of the respondents stated they would prefer to die at home.[1] These values, however, are diametrically opposed to the number of people that actually die at home, the share of which generally hovers around 20 to 30 percent (e.g. Ochsmann et al. 1997; Dreßel et al. 2001; van Oorschot et al. 2004). To distinguish the *imagined* from the *real* place of death, we will provide an overview of the major European studies on the actual distribution of places of death in two synopses (Table 1 and Table 2). The place of death in the wake of cancer is illustrated separately in Table 2. We consider studies in German and English from different European countries and regions. Our aim is to give an overview of empirical trends, the actual distribution, and social regularities with regard to places of death. The literature review is predominantly based on studies that provide official data of the places of death (Ochsmann et al. 1997; Higginson et al. 1998; Davison et al. 2001; Freilinger 2009; Mikulasek 2010; Cohen et al. 2006, 2007; Houttekier et al. 2009). Cohen et al. (2006, 2007) and Houttekier et al. (2009) had privileged access to official data from death certificates, which provide detailed demographic information such as cause, time and place of death, place of residence, age, education, occupation, sex, nationality, and civil status. Thus, the data can be directly used for bivariate and multivariate analysis without having to combine diverse statistical data from different statistical sources as Ochsmann et al. (1997) were forced to do in their study in Germany.

All other studies (listed in table 1) conducted surveys and relied on information on the places of death obtained from the interviewees (patients, family members, and medical staff). Moreover, the studies by Fischer et al. (2004) and Bickel (1998) are based on an analysis of official death certificate data in combination with a survey (interviews with medical staff, n=3358 (Fischer et al. 2004), and family members, n=958 (Bickel 1998)).

The literature review must be viewed within the following limitations. We do not claim to provide a complete review of international studies on places of death. Specific studies about death in hospices, the distribution of places of death for people with dementia (e.g. Houttekier et al. 2010; Verne et al. 2011), for children with cancer (e.g. Shah et al. 2011; Higginson and Thompson 2003), or for people with HIV (e.g. Guthrie et al. 1996) are excluded from the literature review.

The distribution of places of death between hospitals, retirement or nursing homes, at one's own or another person's home varies considerably among countries and regions, as the synopsis in Table 1 shows. Apart from the common fact that hospitals are the most frequent place of death in all studies, the figures given for hospitals as the place of death may differ significantly in a cross-country comparison, for example ranging from 37.2 percent in German-speaking Switzerland (Fischer et al. 2004) and 39.8 percent in Denmark (Cohen et al. 2007) to 63 percent in Belgium (Houttekier et al. 2009). In Germany the percentage of

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[1] http://www.bag.admin.ch/themen/medizin/06082/06426/index.html?lang=de.

hospital deaths ranges from 44.1 (Ochsmann et al. 1997) to 49.7 (Bickel 1998). When comparing this data with Schmied's data (1985: 42) on the proportion of people who died in hospitals in the 1960s and 1970s, we notice relative stable percentages for Germany. The share of people who died in hospitals was at 45.4 percent in 1962, 53 percent in 1972, and 54 percent in 1975. Dying in the hospital varies by region, and various trends have been observed in the past decades. In German-speaking Switzerland, for instance, dying in the hospital has declined from 56 percent in 1969 to 37.4 percent in 2001 (Fischer et al. 2004). In England and Wales, however, it has increased in the periods from 1966 to 1976 (Bowling 1983) and 1981 to 2001 (Ahmad and O´Mahony 2005). While we observe a shift in the place of death from hospitals to retirement and nursing homes, the degree of institutionalised dying remains constant (Fischer et al. 2004). In Belgium, for example, hospital deaths decreased from 55.1 to 51.7 percent and care home deaths increased from 18.3 to 22.6 percent between 2007 and 1998, whereas the percentage of home death remained stable (Houttekier et al. 2011). The incidence of death in retirement or nursing homes also varies strongly by region and country. The number of people that die in one of these facilities has increased while the ratio of increase shows some variation (see table 1). In 2001, 33.5 percent died in a retirement or nursing home in German-speaking Switzerland, which is double the rate in 1986 (Fischer et al. 2004). In Austria, the figures range from 13.4 percent in 1995 to 15.2 percent in 2010 (Freilinger 2009; Mikulasek 2010). Exceptions are the German state of Rhineland-Palatinate at 37.3 percent in 1995 (Ochsmann et al. 1997) and the German city of Jena at 33.7 percent in 2003/2004 (van Oorschot et al. 2005). In Brussels, on the other hand, the rate of those dying in their private home is particularly low at 15.1 percent (Houttekier et al. 2009).

Table 1: Distribution of places of death (data given in percent)

Author	Year	Location	Sample(s) (n)	Hospital	Retirement (RH) and/or nursing home (NH)[1]	At home (AH) and/or other private residence (PR)[2]
Bowling	1983	England, Wales	n.s.	1966: 54 1976: 60-70	n.s.	n.s.
Cartwright	1991	England, Wales	n.s.	n.s.	n.s.	1969: 42 AH 1987: 24 AH
Clifford et al.	1991	Victoria (AU)	n.s.	57	14 NH	21 PR
Ochsmann et al.	1997	Rhineland-Palatine (D)	19,672	44.1	12.8 RH	37.3 AH
Bickel	1998	Mannheim (D)	958	49.7	21.2	n.s.
Davison et al.	2001	Belfast (IR)	n.s.	1977: 50 1987: 40 1997: 42	1977:13 1987: 25 1997: 23	1977: 35 1987: n.s. 1997: 28
Fischer et al.	2004	German-speaking Switzerland	1969: 58,002 1986: 60,105 2001: 3,358	1969: 56 1986: 55 2001: 37.2	1969: n.s. 1986: 14 RH 2001: 33.5 RH/NH	1969: 38 1986: 28 AH 2001: 22.7 AH
Ahmad, O´Mahony	2005	Wales	1981: 35,015 2001: 32,966	1981: 56.7 2001: 61.7	1981: 5.7 2001: 16.2	n.s.
van Oorschot et al.	2005	Jena (D)	90	52.3	12.8	33.7
Cohen et al.	2006	Flanders/BE	55,759	53.7	19.8 NH	24.3 AH
Cohen et. al	2007	Flanders/BE DK SE CH	12,492	Flanders: 50 DK: 39.8 SE: 43.9 CH: 37.3	Flanders: 21 DK: 30.6 SE: 33.6 CH: 33.7	Flanders: 26.5 DK: 25.4 SE: 21.2 CH: 22.7
Gomes, Higginson	2008	England, Wales	n.s.	n.s.	n.s.	1974: 31 2003: 18
Freilinger	2009	Austria	ca. 40,000	50	1995: 13.4/8.4 2006: 15.5/13.5	30
Houttekier et al.	2009	Brussels (BE)	3,672	63	21.6	15.1
National End of Life Care Intelligence Network	2010	England	471,092	58	9 NH 7 RH	19
Mikulasek	2010	Austria	2002: 76,131 2010: 77,199	2002: 55.3 2010: 52.0	2002: 12.5 2010: 15.2	2002: 27.5 2010: 26.83

(Source: own illustration)

[1]: Not all of the studies reviewed make a distinction between retirement and nursing home.

[2]: Here, too, the studies fail to provide information whether the person died in his or her own home or in the home of relatives (e.g. children) or of people that they were close to (e.g. domestic partner).

n.s.: not specified.

Table 2, which gives an overview of places of death in cases of death from cancer, clearly demonstrates cross-national differences in the proportion of cancer patients. The share of cancer patients dying at home or at an institution is much more equally balanced in Germany (Papke and Koch 2007) and Majorca (Catalán-Fernandez et al. 1991) than in Sweden, where most cancer patients die in hospitals (Axelsson and Christensen 1996). Although most of the cancer patients died in hospitals in England, Germany, Switzerland, France, and the USA, the percentage of cancer patients dying at home is higher compared to the number of home deaths listed in synopsis 1.

Table 2: Distribution of places of death for cancer patients (data given in percent)

Author	Year	Location	Description of Sample	Sample(s) (n)	Hospital	Retirement (RH) and/or nursing home (NH)[1]	At home (AH) and/or other private residence (PR)[2]
Catalán-Fernandez et al.	1991	Majorca	Offspring of cancer patients and medical records	335	55	0	45
Axelsson, Christensen	1996	Sweden	Cancer patients	203	64	24 Ph	12
Higginson et al.	1998	England	Cancer patients	n.s.	1985: 58 1994: 47,3	n.s.	1985: 27 1992: 25,5 1994: 26,5
van Oorschot et al.	2004	Jena/ Thüringen (D)	Cancer patients	272/72	59	8	33
Gomes, Higginson	2006	13 countries	1966-2004, Meta-analysis of 58 studies of cancer patients	n.s.	n.s.	n.s.	UK, USA, Germany, Switzerland, France: 1994: 27 2003: 22
Papke, Koch	2007	Saxony (D)	Cancer patients	1997: 331 1998: 326 1999: 310 2000: 343 2001: 319 2002: 357 2003: 330	1997: 48 1998: 46 1999: 50 2000: 47 2001: 45 2002: 54 2003: 51	1997: 4 1998: 7 1999: 4 2000: 7 2001: 10 2002: 7 2003: 9	1997: 48 1998: 47 1999: 46 2000: 46 2001: 45 2002: 39 2003: 40

(Source: own illustration)
[1]: Not all of the studies reviewed make a distinction between retirement and nursing home.
[2]: Here, too, the studies fail to provide information whether the person died in his or her own home or in the home of relatives (e.g. children) or of people that they were close to (e.g. domestic partner).
n.s.: not specified.

In addition, the percentage of all cancer deaths occurring at home was 12.8 percent in Norway, 22.1 percent in England, 22.7 percent in Wales, 27.9 percent in Belgium, 35.8 percent in Italy and 45.4 percent in the Netherlands (Cohen et al. 2010). The proportion of cancer deaths taking place in hospital was 61 percent in Belgium, 31 percent in the Netherlands, 50 percent in England and 60 percent in Wales. In all populations except Norway, the proportion of home deaths was higher in patients with cancer than without (see

Cohen et al. 2010: 2269). Retirement and nursing homes play only a minor role as yet in providing care for those suffering from cancer. According to Cohen et al. (2010: 2271) the underlying reasons for this variation between countries can be traced back to the relationship between patients and physicians or general practitioners, government policies that are clearly directed at care at home, or the development of palliative care predominantly in hospitals. In sum, the differences result from a complex interaction of organisational, societal, and cultural factors (see Cohen et al. 2010: 2271).

Determinants of Places of Death

In addition, studies analyse medical, structural, socio-demographic, and individual factors determining each of these places of death. Those factors thus raise urgent questions for the debate on social inequality. The current state of research illustrates that places of death are not distributed at random but reflect social patterns, which will be summarised below.

The *type of illness or underlying cause of death* is one of the most important factors that determine the place of death. People who fall ill two to three months before death are more likely to die in hospitals compared to those who had been ill for more than two years prior to decease (Bowling 1983). The disorders most frequently leading to death in hospitals are cancer, stroke, and respiratory diseases (Bowling 1983; Fischer et al. 2004; Higginson et al. 1999). Among the different kinds of cancer, bladder and gastric carcinomas are the most frequent causes of death in hospitals (Catalán-Fernandez et al. 1991). Other studies mention breast cancer, haematological and lymphatic disorders (Cohen et al. 2006; Higginson et al. 1999), and neoplasia (Fischer et al. 2004) as the most frequent causes leading to death in hospitals. People dying at home are more likely to do so from cardio-vascular diseases (Fischer et al. 2004; Streckeisen 2001), Parkinson, ischemic heart disease, cerebrovascular, and special types of malign diseases (Cohen et al. 2006). The most frequent cancers leading to death at home are gastrointestinal and prostate cancer in case of men (Higginson et al. 1999) and breast cancer in case of women (Catalán-Fernandez et al. 1991; Papke and Koch 2007).

How might we explain the phenomenon that more cancer patients die at home compared to people not affected by cancer or people with any other illness as shown in synopsis 1 and 2 and observed by Bowling (1983), Fischer et al. (2004), and Higginson et al. (1999)? One explanation could be that suffering from this illness until death usually extends over months and years and typically involves high awareness, knowledge, and pressure to make decisions about further medical treatment by the mostly younger patients. As a result, the conditions required to plan for dying at home are given. Moreover, patients with the greatest likelihood of dying in a hospital are those whose disease takes an unexpected turn or who remain hospitalised while awaiting a vacancy in a nursing home. A patient may also remain hospitalised until death because of the wish to receive treatment to the end (Guthrie et al. 1996). There are different scenarios that could illuminate this wish. First, one reason to remain hospitalised can be traced back to the internalised rules associated with the role of being a patient and the expectation that medical technology still can save one's life. Second, the rules governing the interaction between patients and health professionals can be explained by the "cure" model and the "denial of death" in a modern health system. In brief, the hospital can best be characterised as an institution where the occurrence of death is perceived as a failure of medicine (Howarth 2007). Moreover, the wish to receive treatment to the end could also result from a lack of family members who are available and able to care for the dying person at home. Finally, the wish to remain in hospital can also be attributed to a lack of palliative care facilities in proximity to one's home (Bowling 1983).

The likelihood of dying in a hospital or retirement home increases with the *structural*

availability of hospital beds and places in retirement homes. A low supply in the proximity of one's place of residence increases the likelihood of dying in a private home (Ochsmann et al. 1997). For Swiss language regions, Streckeisen (2001) observes that dying in hospitals takes place much more often in French- and Italian-speaking Switzerland than in the German-speaking parts of the country. The greater incidence of dying outside the hospital setting in German-speaking Switzerland is traced back to the comparatively longer-established and more widespread provision of decentralised care facilities in this particular language region, which facilitates terminal care at home. In contrast to these findings, Ochsmann et al. (1997) did not observe any connection between the availability of out-patient care and an increased likelihood of dying at home. The socio-demographic factors investigated include *age*, *gender*, *family*, and *socio-economic status*. The hospital is the most frequent place of death for the age group under 45 while the proportion of hospital deaths among the age group over 60 declines steadily with increasing age (Bowling 1983; Fischer et al. 2004; Ochsmann et al. 1997). At the same time, the share of deaths in retirement homes rises among that age group (Ahmad and O´Mahony 2005; Bickel 1998; Fischer et al. 2004; Ochsmann et al. 1997). Younger people are more likely to die in a private home, be it in their own home or that of others, than those aged older than 90 years (Fischer et al. 2004; Streckeisen 2001).

Gender has also proven to be a factor of major influence. Men die at home more often than women (Cohen et al. 2006; Streckeisen 2001; Higginson et al. 1999). Family status also has an impact (Bowling 1983; Ochsmann et al. 1997; Streckeisen 2001): Singles without children, especially without daughters, die in the hospital more frequently than widows or divorcees, who are more likely to die in a retirement home. Men and married persons more often die at home (Bowling 1983; Ochsmann et al. 1997). This is considered the result of the higher life expectancy of women and the gendered division of roles and labour between men and women. Domestic care is the domain of women. This corresponds with the female role of the "caregiver" for the dying and is referred to as the "feminisation" of terminal care (Field and Small 1997).

A study on the place of death of cancer patients (Catalán-Fernandez et al. 1991) observed a larger proportion of patients with low socio-economic status dying in the hospital. A low income reduces the probability of dying at home (for a review, see Wilson et al. 2009). The impact of higher social class as a factor associated with congruence between preferred and actual place of death is supported by Bell et al. (2010). Educational level is positively related to the access of palliative care services (Bossuyt et al. 2011). Davison et al. (2001), on the other hand, found no connection between socio-economic status and the place of death.

Place of residence or, rather, *degree of urbanisation* is a factor whose influence on the place of death has been frequently confirmed. Thus, the likelihood of dying in a hospital is greater in urban regions compared to rural areas in Switzerland (Streckeisen 2001). In the countryside, more people die at home, only rarely in retirement homes, for example in Germany or Belgium (Cohen et al. 2006; Gomes and Higginson 2008; Ochsmann et al. 1997; Papke and Koch 2007). Moreover, physician support, hospice and palliative care home services as well as family support increase the likelihood of home death (Wilson et al. 2009; Bell et al. 2010; Houttekier et al. 2010). Having a preference for a place of death and having it communicated with caregivers is an individual factor in determining the place of death. It is a fact that patients who have an advance health care directive die in their place of choice significantly more frequently than those that do not (van Oorschot et al. 2004, 2005).

CONCLUSIONS

Although death and dying remain institutionalised, the sparse data on places of death fail to support the classic thesis of an increasing institutionalisation (Ariès 2005; Kellehear 2007; Feldmann 1990, 1995; Nassehi and Weber 1989). According to Gronemeyer (2005), we are observing the institutionalisation of dying while dying in the family setting remains the "rhetorical ideal". Yet, the characterisation of hospital death as a "lonely death" (Ariès 2005: 730) is an inadequate description of reality and reflects a distorted image drawn by society. Bowling (1983), for instance, shows that in many cases dying people are taken to the hospital only in the final stage after a lengthy period of intensive care by relatives. Hence, the question as to what extent families today are less willing to care for the dying than in the past still remains to be answered (Ochsmann et al. 1997).

The term *institutionalisation* carries the negative connotation of being the typical form of dying in modern service societies. It evokes images of loneliness, isolation and helplessness (e.g. Stephenson 1985; Elias 2002; Gronemeyer 2005, 2007; Göckenjan 2008; Greil 2008). In this largely unexplored area, however, a normative evaluation of places of death as "good" or "bad" is not possible as long as we lack properly defined criteria and empirical findings.

Does institutionalisation amount to a greater publicity of death in society due to the situation of dying leaving the privacy of the individual home, or must we interpret it as a process of suppressing the topic of death and dying (Nassehi and Weber 1989)? Dying in hospitals or nursing homes can thus also be read as the antithesis to suppressing death or rendering it taboo (Nassehi and Weber 1989). Dealing with dying persons becomes visible to a greater number of people when taking place in a public institution. At the same time, hospices and palliative care units establish new forms of institutionalisation and also seek to raise society's awareness of death and dying.

The fairly high and, over many years, constant percentage of people dying at home ranging between 20 to 30 percent additionally casts doubt on the classic institutionalisation of dying thesis. Thus, dying in institutions cannot simply be deemed the "normal case" (Feldmann 2004) in modern society. Moreover, there are signs for a shift from hospitals to retirement homes (Ochsmann et al. 1997). In this context, the consequences of demographic change and the increasing proportion of elderly and single women must be mentioned. Retirement and nursing homes will play an increasing role as places of death and their number can be expected to grow accordingly. Family members will experience greater difficulties in providing care for their loved ones in the future due to increasing participation in the workforce (Fischer et al. 2004; Göckenjan 2008). This fact may also involve a shift in the experience of dying and possibly in the quality of dying since for many people residing in retirement or nursing homes, their retirement or nursing home actually becomes their "home". The culturally pessimistic contention that modern society engages in a "practice of excluding the dying from the community of the living" (Feldmann 1990 – translated from German), which is traced back, among other factors, to the increased employment and social emancipation of women, calls for critical questioning. There is also little evidence for an "erosion of the family" (Gronemeyer 2007) which takes its dying family members to the hospital for lack of time or ability to care for them.

Our review shows that places of death are not distributed at random but reflect social patterns. Dying persons heavily rely on their social environment, its capacity to act and the available resources and institutions. Dying at home is not an opportunity that is equally available to everyone - we first have to create structural conditions that allow people to die in the place of their choice. Socio-demographic relationships involve factors such as gender, socio-economic status, family status, or the degree of urbanisation (e.g. Cohen et al. 2006;

Dreßel et al. 2001; Ochsmann et al. 1997; van Oorschot et al. 2004). Those factors point to social inequalities and thus raise urgent questions for the debate on the place of death. For dying to take place at home, certain conditions must be given: a) individual factors (e.g. a sense of obligation or emotional ties for the motivation of relatives), b) socio-economic factors, and c) institutional and structural conditions (e.g. ambulatory palliative care services). Basic requirements for dying at home are relatives that are able to cope with the situation both physically and emotionally, the availability of ambulatory palliative care, and suitable conditions in terms of space and availability of the necessary technical equipment for care (Wittkowski and Schröder 2008). Receiving physician support, hospice and palliative home care visits have increased the likelihood of home death (for a review, see Bell et al. 2010). Nevertheless, contemporary society is marked by the insufficient availability of hospice or palliative care facilities for the dying in many parts of Europe, both of the in-patient and especially of the ambulatory kind. This affects the rural population more strongly than the residents of urban agglomerations (Bell et al. 2010).

An advance health care directive is an important instrument to record a preference for place of death and communicate with caregivers and physicians (van Oorschot et al. 2004, 2005). In addition, the time frame of events must leave room for weighing opportunities and restrictions in favour or against the respective place of death and allow a deliberate decision to be made. In many cases, fatal illness leaves no choice, and the hospital remains the only option if only for medical reasons. Assurance that proper treatment for symptoms is available, a sense of security, or the desire to relieve relatives of the care burden, are factors that may contribute to explaining the preference for in-patient care (Glaser and Strauss 2007). The studies also point to the emotional burden on relatives as caregivers of the dying (Cohen et al. 2006; van Oorschot et al. 2004) and the psychosocial consequences – an aspect that must not be neglected in the discussion about places of death.

However, the available studies primarily pursue medical or demographic research objectives. The result is that while we do know who dies, where they die, what the medical causes are, what socio-demographic factors are involved, we do not know how the dying or those that act on their behalf arrive at their understanding of the situation or at the decisions to be made or actions to be taken as the process of dying takes its course. The existing studies leave in the dark how perceptions and actions concerning the place of death are affected by the knowledge, wishes, experiences, and emotions of individual actors, by the communication between them, in their social networks, as well as in the setting of the respective institutions. These aspects thus constitute a core desideratum in current end-of-life research.

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Changing Patterns of Alcohol Consumption in Nigeria: An Exploration of Responsible factors and Consequences

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ABSTRACT

Alcohol consumption among different ethnic groups in Nigeria has a long history, especially among those groups where it was not forbidden by religion. In the traditional era, alcohol played complex roles in the socio-cultural relationships of different communities. It was used for rituals, marriage ceremonies, chieftaincy enthronements, etc. It was mainly consumed by male adults for pleasure while females and youths were culturally restrained from drinking. Excess consumption was not a norm and intoxication attracted negative sanctions. In the contemporary Nigerian society, patterns of consumption are changing rapidly following the socio-political and economic development of Nigeria, giving rise to new norms of alcohol use. This review examines the influence of disintegration of traditional values, non-regulation, advertising and other factors on these changing patterns of alcohol consumption. It concludes by exploring the consequences of these changing patterns and suggests some remedies for contemporary Nigerian society.

Keywords: Alcohol consumption, Nigeria, Changing pattern, Traditional values, Non-regulation, Advertising

INTRODUCTION

Alcohol is as old as human history and its consumption in different socio-cultural milieus extends beyond the last ten thousand years (Smart, 2007). Its consumption has been considered normal, especially when drunk without outright intoxication in Africa and other parts of the globe. Wine, beer, spirit and other fermented alcoholic beverages were drunk in traditional societies and some of these beverages are still used in this modern era for different purposes. In Africa, these and other alcoholic beverages such as *palm wine, burukutu,* etc. were consumed for pleasure soon after brewing or tapping (Odejide et al, 1999; Odejide, 2006) and were rarely traded in the market (WHO, 2002). Though alcoholic beverages have been consumed for hundreds of years, the pattern and purpose of consumption vary considerably among societies and even within communities. Excess consumption was not widely tolerated in many societies while few communities permitted it (Willis, 2006). For example, abuse attracted negative sanctions as recorded in the biblical Old and New Testaments (Seller, 1985; 1987).

Drinking of alcohol was culturally tolerated as part of ceremonial lives of many ethnic groups in what is now known as Nigeria, especially in communities where it was not forbidden by religion prior to the advent of colonialism (Heap, 1998; Obot, 2000). A unique feature of this area that is now known as Nigeria was that different locally produced alcoholic beverages distinguished ethnic groups. In the north, *pito* and *burukutu* were commonly consumed. In the south, palm wine tapped from the palm tree (Obot, 2000) was popular while the native gin locally called *ogogoro, kai-kai* (Demehin, 1984; Korieh, 2003), *akpuru-achia*, or *Sapele water*, distilled from the fermented palm wine was widely consumed, especially in the Niger-delta area. Though there were no written rules prohibiting females and adolescents

from drinking in this traditional era[1] (Odejide, 2006), consumption was the reserve of men and played a crucial role in political, religious and socio-economic relationships (Oshodin, 1995). In this era, alcohol played complex roles in religious and communities' rituals and served as a conduit for social cohesion. Because of these ceremonial functions, adult males were expected to drink being served by the youth. Alcohol was a key requirement for a bridal price to be paid in order to consummate marriages in many villages. It was consumed at almost all ceremonies including cultural festivals, chieftaincy enthronements, child dedications and even funerals (Oshodin, 1995).

Alcohol did not just play the role of fostering social cohesion as people drank locally brewed beverages together in groups. According to Korieh (2003), it was also a tool for 'imperial control' and a revenue source for Western Traders. It was also used by 'traditional rulers to exert power over their subjects' (Bowdich, cited in Willis, 2006 p.5). With colonisation and the influx of western cultures, alcoholic beverages from western countries became readily available to old and young, male and female, on a commercial basis.

In recent decades, the pattern, quantity and reason for consumption are changing rapidly, especially among youths (Chikere & Mayowa, 2011). This has resulted in an increased burden of alcohol-related problems, estimated to exceed those relating to tobacco consumption: alcohol misuse can result in death of the user (and non-users, due to drunk driving and other related accidents) and often disability in early years among young people (Jernigan, 2001). It is against this backdrop that this review critically explores the changing patterns of alcohol consumption in Nigeria and its consequences for contemporary Nigerian society. Adopting the public health approach, the aim is to bring to light the changing patterns of alcohol consumption, the factors that necessitate the changes and to advocate for prompt action to remedy the situation through policy and other regulatory measures. The next sections deal with an exploration of the new patterns of consumption and the factors that facilitated these changes. This is followed by the consequences of the new patterns and concluding remarks where the possible remedies are pointed out.

THE CHANGING PATTERNS OF ALCOHOL CONSUMPTION IN NIGERIA

In traditional Nigerian society, alcohol consumption was gender and age based. As noted earlier, it was mainly consumed by adult males in social engagements and customs and tradition regulated production and consumption of locally made alcoholic drinks (Heap, 1998; van Wolputte & Fumanti, 2010). Though young people in a *few* communities were permitted to drink, this was usually in the presence of adults who monitored the quantity they consumed (Obot, 2000). Even in the neighbouring Ghana, elders served as gatekeepers, by deterring younger people from alcohol consumption (Akyeampong, 1996). Alcohol consumption was not a daily affair and it was restricted for use in religious rituals, marriage ceremonies, kingship enthronements, cultural festivals, child naming, etc. that happened in intervals (Ibanga et al., 2005). Even on these occasions, excess consumption among adults was culturally controlled, partly because traditional wine cups were served based on age and title hierarchies (Umunna, 1967). Elders would drink first, served by the younger members of the tribe (Oshodin, 1995) and because the wine was not produced in commercial quantities, this often meant that little would be left for the latter group.

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[1] The traditional era as used in the article refers to the period before the establishment of the first brewery in Nigeria in 1949: it includes the era prior to the contact with western traders in the mid-1660s and the declaration of Lagos as a British colony in 1861, extending to the period before the amalgamation of Nigeria in 1914.

In this era, alcohol was consumed immediately after production, or few hours after production. This is because some of these beverages served as the staple food in some communities and were not meant for sale; and because they were not produced in quantity, since there were no means of preservation. Where trade in alcohol did exist, it was on a remarkably low scale (Willis, 2002). This trend was altered in Western Africa following the influx of European slave traders and their 'trade spirit' in the fifteenth century (Olorunfemi, 1984 p.233). Despite the fact that alcohol was not new to the indigenous people, the influence of the Western traders popularised the sale of liquor and facilitated alcohol abuse due to the importation, sale and distribution of trade spirit (Olorunfemi, 1984; Olukoju, 1991). This trend was sustained during the colonial era and beyond, leading to the establishment of the first brewery (Nigerian Brewery limited presently known as Nigerian Breweries or NB Plc.) in 1946 with its first brew in 1949 (Jernigan & Obot, 2006; Obot, 2000; 2006).

The Guinness brewery was the next to establish its business in 1962 (Obot & Ibanga, 2002) and gradually the sector grew to the point where, in 1984, each of the 19 states had their own breweries (Demehin, 1984). The growth of alcohol industries was partly sustained by the economic boom of the 1970s and sophisticated marketing that promoted industry-produced beer and wine as desirable status symbols among the upper and middle classes. In the process, traditional alcoholic beverages were belittled (Demehin, 1984). This signified, a new trend, in alcohol consumption in the country. This emerging sector was comparatively resilient during the Nigerian economic crisis of the 1980s. A reason for this is that major brewers had nurtured a loyal following, ensuring that their products become household names. Additionally, there was a lack of government regulatory policy. The liberal economic policy of the government enabled brewers to adopt self-regulation. These loopholes on the part of the government arguably opened doors for many other patterns of alcohol consumption to evolve.

In more recent years, there have been some striking changes in the patterns of consumption, brought about by the development of the socio-political and economic structures of the country. Consumption is no longer solely regulated by custom and tradition of the people and it is no longer reserved for social gathering or entertainment of a guest alone (Demehin, 1984). The patterns of use, the users and reason(s) for consumption are changing rapidly, especially among young drinkers.

A sharp contrast from what hitherto existed is the *alcohol contest* among youths in bars, restaurants, drinking joints, hotels and nightclubs that are strategically located near various schools in Nigeria. This competition is always among boys and the winner is judged based on two standards - *the ability to drink large a quantity without showing a sign of intoxication and the ability to drink faster than the opponent*. Here, a large sum of money contributed by these competitors or alcohol marketers (especially those that market spirit) is awarded to the fastest drinker or alcohol *macho.* Marketers do this to introduce new products into the market or to promote existing ones that are not receiving enough sales. Though no study has been identified that focused on alcohol competition in the drinking joints in order to document the negative effects, but the fact remains that it contributes to binge drinking which has precarious consequences on human health (Cismaru et al, 2008; Peasey et al., 2005). In February 2012, a youth collapsed and died in a drinking competition in Lagos (Anonymous, 2012). Among these competitors, alcohol consumption is no longer for *pleasure* as it used to be, but for a *prize*.

Another recent development is an increasing drinking among youths as a means of showing off in *public places*. In the traditional era, youths were restricted from drinking by the norms in most communities. It was permitted within a few communities on festive days, during which

youths were guided by adults (Obot, 2000); but this has changed. Although the minimum drinking age remains 18 years, young people buy and drink alcohol freely in public places. Some of the reasons for this are erosion of communal values, familial socialisation and peer influence. One of the African traditional societal values of brotherliness is increasingly fading away due to globalisation. Therefore, as people become individualistic, they are hardly their 'brother's keeper' as in the past, where adults from one's community applied punitive measure to wayward adolescents on behalf of their parents (in return they received commendations from the latter). Therefore, young people cash in on this loophole to drink alcohol freely. Also, in many families, in Nigeria, parents send their young children to buy alcoholic beverages (Oshodin, 1995) which they then consume in their presence.

This has serious implication because researches have revealed that parents and siblings have enormous influence on the drinking behaviour of young people (Mares et al., 2011; Mares et al, 2012; Poelen et al, 2007; Van Der Vorst et al, 2005). Parental disapproval of adolescents' drinking according to Wood et al (2004), correlates with reduced peer influence. This lends credence to Yu's (2003) findings that parents who restrict their underage children from drinking alcohol at home equally affect their future drinking behaviour. A study conducted among teenagers in Benin City, (Oshodin, 1984) revealed that 85 per cent were current drinkers and 60 per cent revealed they began to drink from their homes while 79 per cent reported that their parents also drink.

The new trend of alcohol consumption among young people contributes to Nigeria's ranking among thirty countries with highest per capita consumption of alcohol globally (World Health Organisation, 2004). These rankings fail to account for the unrecorded production and consumption of alcohol (Jernigan & Obot, 2006). The 2009 report did not indicate a decline in consumption but rather revealed that Nigeria consumed 10.57 Litres per head of the population (Toroyan, 2009). This corroborates Gureje et al. (2007 p.7) findings that 'heavy episodic drinking, rather than moderate drinking is common among users of alcohol in Nigeria' and that alcohol is the most commonly used drug among Nigerians.

Another new trend is the increasing consumption of alcohol by females in Nigeria (Adelekan et al 1993). With the rising influence of globalisation and the upsurge of feminism in the country, women have recently begun to challenge the status quo that relegated them to the background and this seems to have been extended to alcohol consumption. In traditional society, the women hardly drank alcohol because of cultural constraints (Obot, 2006). Additionally, they were not economically empowered. In this contemporary era, many women have acquired education and other skills that enabled them to gain access to paid work. Consequently, many can afford to purchase and consume alcohol. There is also a recent popular maxim among Nigerian women that ''*anything a man can do a woman can do it better*'' (including harmful alcohol consumption), but this has negative consequences because studies have revealed high drinking problems among females in Nigeria (Room & Selin, 2005).

Other recent changes can be inferred from the findings of recent research conducted among undergraduates in Owerri, Imo State. The respondents gave some reasons why they currently use alcohol and these included: to enhance sexual pleasure, to *feel high* and to feel more sociable (Chikere & Mayowa, 2011). This is arguably linked to the way Guinness Extra Stout is portrayed in the advertisement as a vitality-enhancing beverage using young, partying people as models. The findings revealed that 11 per cent initiated alcohol use between the ages of 11 and 15; 45 per cent initiated drinking between the ages of 16 and 20 and 26.7% can be said to be binge drinkers (Chikere & Mayowa, 2011).

Alcohol in Nigeria has also assumed different *roles* as drinking patterns are evolving. Some

alcoholic beverages are now associated with class status symbols or a sign of recognition of subgroups. For example, the elites display different bottles of *foreign* wine in their private bars as signs of affluence. Some social occasions do not permit the use of particular locally produced beverages *because they are not fit for the class involved.* In some communities, bridal price will not be accepted from the groom without presenting cartons of 'Guinness Stout' and bottles of schnapps to the elders. This is contrary to the traditional era where male adults drank *locally made beverages*. In fact, among the Ubulu people of Delta State, this schnapps is called *maya-jeakwa (a drink that wore cloth)* rendering it as superior to the locally produced palm wine which comes in 'calabashes'*.* It is also worth noting the use of alcohol in deception by taking *alcoholic herbal mixture*. A very fascinating thing is that this is done by those who drink alcohol and those who are constrained by socio-religious factors. This is produced from a mixture of *ogogoro* with herbs or root of trees and administered as medications. In different parts of the country, this product is sold by vendors in motor parks (Kehinde & Olusegun, 2012; Oluwadiya, 2010) and the implication is that commercial drivers are some of the patrons. Some parents also administer it to their young children when they are sickly (Oshodin, 1984) contributing to the early alcohol initiation.

Factors Responsible for Changing Patterns of Alcohol Consumption in Nigeria

A major contributor to the changing patterns of alcohol consumption is the absence of alcohol policy in Nigeria. Globally, alcohol producers often frown at strict measures to regulate the production and marketing of alcohol through legislation due to economic interest (Miller et al, 2010). They often claim that restriction will reduce sales which will result in job loss. They solicit for self-regulatory 'responsible drinking', but this has been revealed to be highly ineffective in controlling alcohol misuse (Bakke & Endal, 2010).

In developed societies, policy makers always set the standard measurement of alcohol in volume and value. This helps to determine what responsible consumption is for adults who are legally qualified to drink. In UK for instance, the standard value of the unit of alcohol is 7.8 grams and women and men's maximum of drinks per week are 14 and 21 standard drinks respectively. Against this background, pregnant women or those who are likely to get pregnant are advised not to consume alcohol within the period of conception (Farke, 2011). Therefore, responsible drinking can be said to be consuming not more than four units for men and three units for women per day. In Australia, a standard drink contains 10g and males and females respectively are advised not to exceed four and two standard drinks daily (Jones & Gregory, 2009). In the USA, similar definition exists because the standard value of the unit of alcohol is 14 grams or 17.7ml and since 1989, the US government made it compulsory for all alcoholic beverages produced or imported to carry a warning message on their labels (DeCarlo, 1997).

In these countries, alcoholic containers carry alcohol by volume (ABV) and warnings on their labels as a means of informing consumers appropriately on what constitute responsible consumption. Though the effectiveness of warning labels on alcohol has generated debate for producing mixed results (Ringold, 2002), research findings have revealed that labels enhance awareness of the information they carry (Wilkinson & Room, 2009) because they help to reinforce 'already known hazards' (Kaskutas & Greenfield, 1992 p.12). Warnings encourage safe behaviour (Cox et al, 1997) while those that have coloured pictorial warnings enhance 'noticeability of warning information' (Laughery et al., 1993 p. 48) thus contributing to positive results. Many other countries such as Australia (Midford, 2005) and Sweden (Babor & Winstanley, 2008) have recorded success in alcohol policies and strategies. The success of Sweden comes from the increased alcohol tax, which led to the reduction of alcohol-related negative consequences.

Although Nigeria and many other African countries contribute to the global burden of alcohol-related problems due to increasing harmful use, only a few countries within Africa have policies to regulate alcohol use and misuse. Even those that have policies, the vested interest, which affects not just Africa, but the other part of the world (Babor et al, 2010; Bakke & Endal, 2010; Miller et al, 2011) can render policy ineffective and subject to misuse. A Global call to regulate alcohol through policy became paramount out of the recognition of the rising harm caused by misuse. Therefore, a World Health Assembly resolution in 2005 had to call the World Health Organisation to work hand-in-hand with Member Countries to formulate policy aimed at checking alcohol misuse (WHO, 2005). Ten key policy strategies were, therefore, adopted in May 2008 (World Health Organisation, 2009). Since then, Nigeria has not formulated any policy to regulate alcohol use and misuse. It instead has continued to rely on self-regulation, as championed by alcohol producers who market their alcoholic beverages through sophisticated strategies while at the same time supplanting stringent policies from being pursued (Babor & Winstanley, 2008; Casswell, 2011).

Alcohol policies do exist in South Africa, although a move to ensure that alcoholic beverages carry warning labels did not come to fruition until 2009 (Parry, 2010). Since then, it has become mandatory for alcohol products to carry at least ''one of the seven health messages and be at least one-eighth of the total size of the container label'' (Parry, 2010 p.1341). A unique character of South Africa's policy is that it is quite comprehensive compared to other African countries' policies; it has also begun to produce results. Some aspect of the policy came from the findings of research sponsored by government agencies (Parry, 2010). Indeed, more alcohol research has been successfully conducted in South Africa than any other part of the continent (Parry, 2005). In Nigeria, there is limited manpower to facilitate researches due to out-migration of experts (Babor & Winstanley, 2008) and due to total neglect on the part of the government. The government provides remarkably little funds for such research and the findings from individual-funded research that would have aided policy formulation, end up in the university library shelves without implementation.

Alcohol policies also exist in Botswana. Stringent measures were recently introduced, one of which involves an increase in the liquor levy, in an attempt to regulate alcohol in that country (Pitso & Obot, 2011). The unique aspect of this policy is that the revenue from the liquor levy is used in programmes that are channelled toward reducing abuse of alcohol by empowering the youths economically. This measure is aimed at helping youths who drink due to idleness to become meaningfully engaged in other activities. Another part of the policy is to regulate further, the activities of alcohol producers (Pitso & Obot, 2011). Other African countries that have policies are Lesotho, Malawi and Uganda (Bakke & Endal, 2010) and the most recent is Kenya (Obot, 2012). Despite the fact that some of these policies are fraught with inadequacies due to the influence of alcohol producers' high input on the policy process (Bakke & Endal, 2010), there is, nonetheless, some legal framework that can be improved upon within these countries.

In Nigeria, there is no policy to regulate the production, marketing, advertising and availability of alcohol that are giving rise to the changing patterns of alcohol consumption. The country relies on the 'self-regulatory' *drink responsibly* campaign by brewers. This campaign is never comprehensive because it involves awareness programmes via posters (Obot, 2007), seminars (Odejide et al, 1989) and placards to disseminate information that recommends moderate drinking rather than abstinence. This campaign can arguably be regarded as an advertisement and public relations to boost the image of the brewers rather than anti-drinking. This is because the campaigners wear branded T-shirts bearing the names and products of the brewers and it does not recommend *zero consumption even to drivers that are the target*. Additionally, the campaign has been championed by the brewers and the

International Centre for Alcohol Policy (ICAP). ICAP is an organisation financed by multinational alcohol producers to influence policies that favour consumption rather than abstinence (Babor, 2010; Babor & Xuan, 2004). The campaign, therefore, is strategically loaded. It is driven by a hidden agenda and represents a paradox of deception as it aims to create a good image of their companies via what superficially appears as social responsibility and also to distract any call for meaningful policy that will reduce consumption (which is likely to mar their businesses).

In the first place, before any country can determine 'responsible' or 'irresponsible drinking', there must be a clear definition of what a *standard drink* is for legally qualified consumers. In Nigeria, there is no definition of a standard or responsible drink by the government or the brewers and alcohol containers come in varying sizes and shapes and do not carry alcohol by volume (ABV) on their labels. Even locally made alcoholic beverages are packed and served in different sized bottles and glasses. There is no basis, therefore, for judging a responsible drink.

Other contributors to the changing patterns of consumption are the easy accessibility of alcohol and lack of implementation of the minimum drinking age by both the government and the brewers. Though an 18 years legal limit exists (on paper), many social constraints hinder adherence in Nigeria. Presently there are no means of identification of minors (or even adults) in Nigeria due to the failure of national identity card projects and the police do not arrest those who sell to minors. In bars and restaurants, young girls are strategically employed as sales girls in order to attract males to patronise the drinking joints. This encourages alcohol initiation, use and abuse because these young girls, who may not have been drinkers prior to their employment, may learn to drink as they serve these male patrons in order to satisfy their employers. In South Africa, Parry (2010) reported that part of the alcohol policy is aimed at protecting minors by ensuring that people less than 18 years are barred from selling or buying liquor. Such policy does not exist in Nigeria; the 18 years benchmark is flouted with impunity and some of the activities of brewers such as *night shows* facilitate this.

The locally produced gin (ogogoro) that was illegal in the colonial era was legalised in post-independence (Demehin, 1984). The reason for this legalisation appears similar to what happened in Ghana, where economic interest overruled public health interest (Luginaah, 2008). This gin has some unique features- it is often produced in an unhygienic environment and it contains a high level of alcohol by volume (ABV) that is over 20 per cent. The neglect from policy makers has existed since the early 1970s according to Anumonye et al (1977 p.27):

> So far alcohol has not received the attention it deserves in Nigeria. It is increasingly abused. This abuse will become a serious problem within the next few years since: the prohibition on the formally illicit locally brewed gin has been lifted… beer breweries proliferated apparently for political purposes… Local distilling of gin has recently received government blessing…

Presently, bars, restaurants, hotels, etc. sell alcohol at any time of the day. There is no policy on *time, day, place and who* can sell or buy alcohol, nor is there enforcement of any law that prohibits sellers from selling to alcoholics. In Botswana, there is a policy on liquor sale where sellers are permitted to sell between 9 am and 11 pm 'except on Sundays, Good Friday and Christmas Day' (Pitso & Obot, 2011 p.902). The South African policy has a clause that made *training of sellers* a requirement and some sales outlets have had to be closed down (Parry, 2010) in order to limit easy access; such does not exist in Nigeria at present.

Other significant contributors are advertising, promotion and marketing which are getting

more sophisticated and are highly unregulated. Popular musicians and footballers are employed to promote their products. Drinking of alcohol is glamorised and associated with success. They employ both foreign and local models and musicians (Obot & Ibanga, 2002) to promote their products. In some of these promotions, free drinks, money and other souvenirs are given out to lucky winners. This has serious implications: A recent study by WHO Regional Office for Africa revealed that 14-year-old boy said that *'if I don't see the stout ad on television I feel bad'* (De Bruijn, 2011 p.37) and has developed an interest in drinking stout because he admires the advert. Also, another 14 years old girl said that she likes *Sta*r advertisement (a product from one of the major brewers), *'because you can win so many things, for example, free drinks'* (De Bruijn, 2011 p.37).

In order to attract more youths, brewers sponsor a variety of social events, including *Star Trek, Star Quest, Heineken Champions League viewing centres* (by NB Plc.), *Guilder Ultimate Search*, etc. This arguably is one of the reasons why industrial beer has become the most preferred alcoholic drink in Nigeria. A unique feature of these events is that youthfulness is a criterion for registration and participation. Winners may go home with new cars, cash (in millions) and in most cases, a musical record deal. These events that run over the course of several months are often held in main cities in Nigeria. Other features of the events are that they are mainly night events and youths are admitted freely or with minimal payment. In these events, young people (including those that are below 18 years) attend and in most cases offered free drinks or at reduced prices. These events receive wide coverage by the media including the government-owned media and some of them are staged in government properties such as the stadium and the national theatre. The implication of this is that these producers are not just encouraging alcohol initiation, use and misuse, but are also nurturing future patrons as alcohol consumption is portrayed in a positive light.

The Consequences of the Changing Patterns

The consequences of harmful alcohol use cannot be denied in the present world. It has social, health, economic, psychological and many other consequences (Klingemann & Gmel, 2001). In Ghana, consumption of the locally made gin has been linked to an increase in violence in local communities (Luginaah & Dakubo, 2003) and this is almost a daily occurrence in most Nigerian higher institutions (Rotimi, 2005). In many schools, in Nigeria, cult clashes have been on the increase and youths cruelly maim their rivals with dangerous weapons. This has been linked to the fact that alcohol is hazardously used among Nigerian youths, including undergraduates (Adewuya, 2005) as drinking joints are strategically located in and around schools. There is also increasing violence in many communities linked to alcohol misuse (Obot, 2006) and many incidences of wife battery and familial violence (Brisibe et al, 2012).

Though moderate alcohol consumption may enhance the control of coronary heart disease (Anderson & Baumberg, 2006), misuse has been linked to heart disease (especially as the user grows older) (Anderson & Baumberg, 2006). It also causes liver disease (Reuben, 2006; Reuben, 2007; Reuben, 2008; Zakhari & Li, 2007) for which there are as yet no effective 'treatment advances' (Reuben, 2007 p.283) in Nigeria. There is the option of transplantation (Reuben, 2008), but only a few can afford the cost in Nigeria. There is also a serious problem of how to determine moderate consumption in a country where there is no definition of a standard drink, no inclusion of alcohol by volume on labels and where alcoholic beverages are served in different sizes of bottles, cans, glasses and calabashes.

Harmful alcohol use by pregnant women affects the unborn child leading to foetal alcohol syndrome (Jones & Smith, 1973). It leads to malformation of the brain in the unborn (Clarren et al, 1978; Jones et al, 1973) resulting in birth defects (Jones et al, 1974). In Nigeria, there

are no effective means of deterring this because there is no warning against drinking during pregnancy. The 'drink responsibly' message does not recommend zero consumption even among pregnant women. The fact that women are beginning to drink even more than men now in Nigeria (Gureje et al., 2007) means that the country may continue to witness birth defects. Among the Ubulu people of Delta State, drinking of palm wine is highly recommended for pregnant women and nursing mothers as a means (myth) of enhancing breast milk. Though palm wine is low in alcohol by volume, continuous consumption of this sweet soluble may contribute to birth defects.

Another major consequence of the changing patterns of alcohol consumption is road traffic accidents due to drunk-driving. This has continued to claim lives yearly in Nigeria (Aworemi et al, 2010) and may continue because *drivers are advised to drink responsibly by the brewers rather than to abstain*. Nigeria presently ranks third out of the 10 countries with the highest number of deaths related to road accidents (Toroyan, 2009) and the problem may continue due to lack of policy to check alcohol availability, use and misuse. The sale of ogogoro is not regulated and the brewers are increasingly campaigning for moderate consumption among drivers, while at the same time supplying their beverages to commercial motor parks.

CONCLUSION

The review has shown that there is an urgent need to formulate policies in line with 10 proposed targets of WHO 2008 resolution on 'strategies to reduce the harmful use of alcohol' (WHO, 2009) in Nigeria. Policy makers and brewers should reconsider their economic interests and arise to the global call for action against the rising alcohol-related problems, of which Nigeria is a major contributor. There is a need to define what constitutes a standard drink and mandate labels to convey this definition. Campaigns should focus on rural areas initiatives rather than focus on the cities. This is because the majority of Nigerians live in the villages and they are the ones involved in local brews of ogogoro. Prices of beverages should be raised and, the activities of the brewers that have been making alcohol available to all should be curtailed.

There should be a total ban of advertising that paints alcohol consumption as good for youths and promotions that promise to offer free drinks should be also be banned. There is also a need to ban night events organised by brewers and re-orientate youths' perceptions of alcohol use. As research findings have revealed that the use of salient posters, pictorials and interchangeable messages on the cigarette are effective in encouraging behavioural change (Argo & Main, 2004; Hammond et al, 2004; Borland et al., 2009), these should be part of the policy. This is because many Nigerians are still below literacy level and may not be able to understand textual warnings. Until these remedial measures are taken, other harmful patterns and reasons for alcohol consumption in Nigeria may continue to emerge.

Acknowledgements

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Cochlear Implants and Identity Politics: A Parent's Perspective

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ABSTRACT

Most deaf children (90%) are born to hearing parents and yet hearing parents are largely missing from the literature on both sides of the cochlear implant debate. The scientific papers and books are written by professionals for other professionals, or by professionals to share expert advice and opinions on how to parent a deaf child with parents of deaf children. The arguments presented by the Deaf community and disability theorists are open to a wider audience but again tend to focus on explaining a particular position in which the hearing parent is 'othered' as a potential threat to the Deaf community. There are some studies which explore the ways in which parents make decisions about cochlear implantation for their children but these tend to address practical issues rather than the theoretical arguments for and against implantation. This paper seeks to redress the balance and provide a critique of the cochlear implant debate from the viewpoint of hearing parents of a deaf child.

INTRODUCTION

The vast majority (90%) of deaf children are born to hearing parents (Balknay et al. 1996). They are not born into, brought up in, or surrounded by, the Deaf community. Deaf children of hearing parents may 'join' the Deaf community if they attend deaf schools or youth clubs but there is no automatic 'right of passage' for these children. Joining the Deaf community may actually be quite difficult for deaf children of hearing parents as it relies on the actions of their hearing parents. Parents need to act as a conduit and seek out the Deaf community, which, itself, raises practical and emotional issues for the parents. Practically there is a need to seek out the community and the ways in which it can be interacted with, there are language issues for parents with little or no knowledge of British sign language, and there is the emotional challenge of seeking out a community for your child that may both separate them from the community in which you live and into which they were born and is a community into which you, as a parent, cannot easily fit. These are some of the issues which directly affect hearing parents of a deaf child and they are issues which will be addressed in this paper in relation to the cochlear implant debate.

There are plenty of papers exploring the cochlear implantation of deaf children and adults. Scientific papers focus on technological developments in implants, both in relation to the hardware and the software for these devices (Cooper and Craddock 2006), surgical techniques and processes (Graham 2006), and the audiological and neurological impact of these devices on the ability to process and make sense of sound (Nittrouer & Chapman 2009; Geers, 2004; Nittrouer, 2009). Psychological work looks at the impact of implantation on social interaction and family dynamics (Weisel et al. 2006; Zaidman-Zait 2007; Huttunen and Valimaa 2010). There are also papers on teaching children with cochlear implants and a

whole range of booklets and leaflets aimed at supporting the parents of children with cochlear implants, both through the assessment process and beyond (see the National Deaf Children's Society or Ear Foundation websites for examples). More recently a study has emerged which focuses on deaf teenagers reactions to their own implants (Wheeler et al. 2007). Concomitant with the scientific, medical, therapeutic and parent support literatures is a body of work stemming from the Deaf community and disability literature. This work largely focuses on the problems associated with medicalising deafness and the ethical implications of implanting young children, either per se, or prior to their ability to make an informed decision themselves. Some of the recent work has suggested that cochlear implants threaten the Deaf community through the creation of oral deaf people (Levy 2002), that cochlear implants are about cultural assimilation and that this is morally corrupt (Lane and Bahan 1998) and that all work on cochlear implant technology should cease to prevent the further erosion of the Deaf community (Sparrow 2010).

Hearing parents are largely missing from the literature on both sides of the cochlear implant debate. The scientific papers and books are written by professionals for other professionals, or by professionals to share expert advice and opinions on how to parent a deaf child with parents of deaf children. The arguments presented by the Deaf community and disability theorists are open to a wider audience but again tend to focus on explaining a particular position. There are some studies which explore the ways in which parents make decisions about cochlear implantation for their children (Hyde et al. 2010; Weisel et al. 2007; Archbold et al 2006), but these tend to address practical issues rather than the theoretical arguments for and against implantation. This paper seeks to redress the balance and provide a critique of the cochlear implant debate from the viewpoint of hearing parents of a deaf child. As convention dictates, throughout this paper, the term 'deaf' is used to indicate people with audiological hearing loss, whilst 'Deaf' signifies people who self-identify as members of the Deaf community. The paper starts with a brief overview of the authors' credentials as the hearing parents of a deaf child with sequential contralateral cochlear implants. The main arguments within the cochlear implant debate are then reviewed before a parent's perspective is offered. The paper concludes with some thoughts about the future for cochlear implanted children and the Deaf community.

BACKGROUND

Hearing loss is a very small part of our son and we do not want to give the impression in any way that we see him through his hearing loss. For this reason, this section of the paper is split into two parts. The first part presents a brief hearing history incorporating the process of cochlear implantation and the second part reflects our perspective on the process of cochlear implantation, the decisions that we made as the parents of a deaf child and the reasons behind those decisions.

Our Story

Our son was born three weeks after the introduction of the newborn hearing test locally. We had some concerns in the early months as he seemed to respond to some sounds some of the time but his responses were not consistent. He appeared to pass his distraction hearing test at eight months, largely through natural curiosity, and it was not until he was 15 months old that we requested a further hearing test through our health visitor. Having failed two tests locally and we were then referred to the main paediatric audiology department. When he was 22 months old, three weeks after the birth of our second son, we were told our son had a moderate to severe hearing loss and would need hearing aids. We got our first hearing aids two weeks later and he adapted to them fantastically. They made a difference but he still had

no access to some of the higher frequency sounds. Subsequent audiology assessments reclassified him in the severe to profound range and we were provided with state of the art Naida hearing aids. Again these made a big difference and gave him access to sounds that he had not previously heard but we were warned that it was unlikely that he would be able to access the high frequency speech sounds even with these aids. Around the time of his third birthday we requested a referral for a cochlear implant assessment. Several months and a whole series of assessments, meetings and discussions later our son was accepted for cochlear implants. He was offered two (bilateral implantation) but at that time we all felt that binaural hearing (uni-lateral implantation with a hearing aid in the non-implanted ear) would offer him the best access to the widest range of sound. Funding was requested and agreed and we awaited the operation date with trepidation and hope.

When he was three and a half my son had his first cochlear implant operation. We were admitted to the ward on the Thursday evening and the operation was scheduled first thing on Friday morning. It is difficult to describe the emotions of the journey to the operating theatre and the agonising five hour wait to be told that he was in recovery and we could go and collect him. Suffice to say we were glad we would not have to go through it again. We arrived in recovery to hear him calling for us, awake, upright and already remarkably alert. We were taken back up to the ward and within an hour he had devoured two ham sandwiches and some ice cream and was ready to play. Our biggest problem over the next two days was keeping him still. He was discharged on the Monday and we spent the next two weeks in quarantine, avoiding crowded places and large groups of people. A week later we arrived at the implant centre for the switch on. It went really well and we had a series of visits over the next weeks and months to tune and fine tune the device to give him the best possible chance of gaining useful sound. As with his hearing aids, he adapted to the cochlear implants brilliantly and wore them constantly. His listening skills continued to develop, his vocabulary widened, his speech got clearer and he was able to talk to, and be understood by, his friends at nursery. Again we worked hard to make the cochlear implant a positive part of our lives and were so successful that we had to explain to his younger brother why he could not have one too. Trips to the implant centre always involve a cake stop in the local café and the processor was personalised with a range of stickers chosen by our son on a daily basis. He decorated it, owned it, and was proud of it.

Three months after his fourth birthday we began to feel concerned as our son did not seem as responsive as he had been to sound in his aided ear. He told us that his hearing aid was not working and asked for a second cochlear implant. We requested a hearing test and on the 27th January 2010 we were told that he had lost almost all of the remaining hearing in his non-implanted ear. The shock was huge but this time the decision was far easier, the first implant was a huge success, he had asked for a second implant and he had virtually no residual hearing left to lose. We phoned our key contact at the implant centre the next day and asked how to start the assessment process for a second implant. Our MRI and CT scans were very recent and did not need repeating and the ear had been cleared for implantation less than a year earlier so we only needed to complete some questionnaires, have two repeat hearing tests to confirm the loss and attend a parent information session. The PCT took less than 24 hours to agree the funding for the operation and two months to the day after we received the diagnosis (a year to the day after his first implant operation), our son received his second implant. Again we were in hospital for four days but this time in a ward with three other children also receiving cochlear implants, one being one of our son's closest friends also receiving her second implant. The support and companionship made the stay easier for all of us.

The same process of quarantine and post-operative checks were carried out and 6 weeks

later we arrived at the implant centre for the switch on of the second implant. It was set very low and switched on. Our son continued playing and wore the processor happily. We were given three programmes, each louder than the last with instructions to gradually increase the volume to give access to sound. On the way out of the centre he turned to his father, grinned and said "now I can hear". By the time we reached the car he had decided the first map was too quiet and asked to have it turned up. The tuning process proceeded very smoothly. He loved his new implant and refused to take the processor off, even at night, falling asleep with the processor on for the first two months post switch on. His listening skills improved, his vocabulary started to grow again and his speech got clearer. He started mainstream school (with a statement of special educational needs, a soundfield system, a radio aid, fantastic support from all of the professionals involved in his care and new Buzz Lightyear and Woody stickers for his processors) five months after receiving his second implant. There is a lot more that could be said about the time invested helping our son to develop his speech, the support that we have received, the vast number of people who have cared, supported and worked with us on the journey so far, but at the heart of it is a determined, confident, happy little boy who wants to communicate, talks continuously and, in his own words, loves his cochlear implants.

Reviewing the Arguments

There are two main streams to the arguments against the cochlear implantation of deaf children. The first focuses on Cultural assimilation, hinging on the parallel drawn between the deaf community and other minority linguistic communities and viewing cochlear implants and oralism more widely as a form of 'ethnocide'. The second, focuses on the idea of the 'normalisation' of abnormal, imperfect, or tragic deaf children and adults to allow them to be productive members of the majority hearing world.

Cultural Assimilation

Sparrow (2010) uses the threat of linguistic annihilation to explain some of the more outspoken attacks on cochlear implantation from within the Deaf community. "Imagine that you are a member of a minority linguistic community … in the not too distant past members of your community have been imprisoned and tortured for daring to use their own language. Perhaps in response to the persecution they have faced in the past, members of your group tend to be fiercely proud of their cultural community." (Sparrow, 2010: p456). Cochlear implants are simply the latest in a line of 'historical genealogies of Deaf subjugation' (Cambell 2009:93) whereby the majority hearing population seeks to dominate and impose their values on the minority Deaf community. In the words of Ladd (cited in Blume 1997) cochlear implants are "Oralisms Final Solution". The argument then follows that children implanted in childhood are forcibly removed from Deaf culture and assimilated into the majority hearing culture without their consent. Crouch (1997) views deaf children with cochlear implants as outsiders who no longer fit within the Deaf or hearing communities, sentiments echoed by Campbell who suggests that cochlear implants create "hybrids destined to live in the twilight zone" (2009:95).

It is worth noting, however, that this argument of cultural assimilation can only be used in relation to deaf children of Deaf parents. It could feasibly be argued that pressure to communicate orally forces these children to assimilate to a culture other than that of their parents. The same can not be said, however, of the deaf children of hearing parents (90% of all deaf children (Balknay et al. 1996)). Far from forced assimilation to an alien or 'other' culture, in this case, the development of oral communication as the primary means of communication in these children allows them access to their own culture. As Hyde et al. (2010) found: "…parents placed great importance on their children sharing their own social,

cultural and linguistic traditions" (2010: 175). Following this argument, one could go so far as to argue that refusing to allow deaf children to receive cochlear implants itself forces deaf children of hearing parents into cultural assimilation with an alien culture. This said, research by Li et al. (2004) suggests that the beliefs, values and attitudes of parents, particularly in relation to the desire for their children to be oral and participate in mainstream society affects the likelihood of parents making a pro-cochlear implant decision. Thus the parents strength of attachment to their own culture can be seen to affect the degree to which they fight to ensure their children's inclusion within that culture (Archbold et al. 2006).

Further to this, in an exploration of the history of the American Deaf community, Rosen (2008) suggests that Membership of the Deaf community is more about attitude than audiological status. Drawing on the work of linguists such as Padden and Markowicz (1975) and Baker and Padden (1978), Rosen argues that it is attitude that explains "why some hard of hearing people see themselves as deaf, why some profoundly deaf people see themselves as hearing and why some hearing children of deaf parents refuse to speak but instead prefer to sign." (2008:136).

Cochlear Implants as Normalisation

Discrimination and oppression leading to inequalities in educational achievement, employment opportunities and life chances are highlighted by Sparrow (2010). He suggests that the limitations on opportunities available to deaf children are due to 'organic dysfunction' and not just minority linguistic status. Thus he argues that the inequalities experienced are not simply due to a language issue. Following this argument, cochlear implantation stems from, and results in, normalisation, rather than cultural assimilation. This goes to the heart of the argument as to whether deafness is a disability or a difference. Some members of the Deaf community go so far as to suggest that deafness is not simply a difference but a positive state to be sought (Lane et al. 1996). This ties in with work by Tucker (1998) in the US and Middleton et al (2001) in the UK who found that many Deaf families actively want deaf rather than hearing babies. An information leaflet published by ASL-info (2003) suggests that deaf behaviour, knowledge and values, alongside fluency in signed language, are assets in the Deaf community. They go on to state that "Deafness is not a disability but rather a different way of being". It is not difficult, when viewing the cochlear implant debate from this standpoint to see why some members of the Deaf community are so against cochlear implantation. If deafness is an integral part of Deafness and Deafness is a positive state, then cochlear implants are simply unnecessary and risk making it more difficult for deaf children to become Deaf.

In her work charting the emergence of the cochlear implant industry in Australia, Campbell (2009) suggests that cochlear implants can only be heralded as a technological miracle if deafness is seen as a disability and therefore as intrinsically negative. Such a consensus was required to make the cochlear implant agenda work as it hinges on the idea that deafness needs to be cured. Thus the presence or creation of 'sound' takes on a moral status and cochlear implantation becomes ethically valid. Campbell traces this back to the sound good/sign bad debate which was epitomised by the banning of Australian sign language (Auslan) in deaf schools in the 1880s. In his earlier work, Crouch (1997) further suggested that many among the hearing majority see deafness as a tragedy and it is therefore unsurprising that hearing parents of deaf children seek medical assistance to 'cure' their children. This raises the question as to whether hearing parents of deaf children view their children as 'abnormal' and wish to 'normalise' them or whether, as research involving parents (Hyde et al. 2010, Huttunen and Valimaa 2010) tends to suggest, the majority want to maximise the opportunities available to their children. Nonetheless the perception remains

that cochlear implants normalise deaf people and make them 'aesthetically valid' (Hughes 2000; Lane and Grodin). Taking this argument to the next level, Campbell (2009) argues that not only do cochlear implants stem from a desire to normalise deaf people, she uses the work of Foucault (1997) to illustrate how the burden of responsibility for the perceived success of cochlear implantation is shifted to the recipients, or, in the case of children, to their families. "Acceptance into the programme requires the candidate (and their families) to be motivated, productive and compliant with the therapeutic regime installed as [art of the implantation package." (Campbell 2009:91). Here the argument against normalisation ties in to the argument against cultural assimilation and comes full circle. "Deafness is not a disability. Instead, many deaf people now proclaim, they are a subculture like any other. They are simply a linguistic minority ['speaking' sign language] and are no more in need of a cure that Haitians or Hispanics". (Dolnick 1993:302). The counterarguments to the cultural assimilation would then apply.

A PARENT'S PERSPECTIVE

From Our Perspective

This is a subjective view but represents a reflexive account of our experiences of cochlear implantation with our son. When we were first told that our son had a hearing impairment we went through all of the usual stages of shock and grief. How had this happened, what had caused it and was it our fault? We both had friends at school who were well adjusted, successful and deaf, however, so we were less negative about the diagnosis than we may otherwise have been. It was not until we began the process of audiological assessments, hearing aid assessments and speech therapy and made contact with our teacher for the deaf and community paediatrician that we began to realise the enormity of the potential impact of hearing loss. Our son is an affectionate, happy, bright and sociable little boy who desperately wants to communicate. The idea that this may be harder for him than for other children, not just in the short term but throughout his life, was heartbreaking for us as parents. He adapted to his hearing aids well though, and we adjusted to seeing him with them and worked hard to make sure they were a positive part of his life. He had pictures in his ear moulds and trips to the hospital always came with a chocolate iced bun. Our first encounter with a cochlear implant was when we joined a pre-school for hearing impaired children and met children with implants. Great children who remain friends, but we were so glad that at least our son would not need an implant.

Deciding to seek a cochlear implant for our son was the hardest decision we have ever had to make as parents. We would be giving our son the best possible chance to hear all of the sounds of speech and access high frequency speech sounds that he would never access in any other way. And yet there is no guarantee that an implant will work or that it will result in clear, intelligible speech. Not only was there no guarantee of success, the operation would most likely take away all of the remaining hearing in his implanted ear and so, if unsuccessful we would actually leave him in a worse position than prior to the operation. And then there was the surgery itself. We would be subjecting our child to a long operation with all of the associated risks and with no guarantee of success. Even if the operation was a success he would have a weak spot on his skull, there would be certain sports and activities that he would not be able to participate in and we would be making him stand out, an object of curiosity. In addition we were aware of the debates around cochlear implantation and sign language and the controversy surrounding the whole process, and we read widely prior to making our decision, but this was of little relevance to our decision. We were not choosing an implant through hatred of deafness or a desire to eradicate the Deaf community. We chose

an implant to give our son what we felt was his best opportunity to develop the ability to communicate independently with as many people as possible. The second implant was a far easier decision for us, made with the knowledge that the first implant was a huge success, that our son wanted a second implant, and that he no longer had useful residual hearing to lose.

CONCLUSIONS

Hintermair and Albertini (2005) argue that it is the either/or philosophy (Enterstvedt 1999) that causes the problem when looking at the cochlear implant debate and the impact of cochlear implantation on the Deaf community. They argue that a cautionary approach is needed when approaching the issue and that parents should be provided with objective information on the pros and cons of cochlear implants along with the time and space to make a reasoned decision. This type of inclusive both/and method was deemed more effective. Having experienced the intensive cochlear implant assessment process twice, as both the parent of a potential unilateral candidate and for a second (sequential contralateral) implant, there is little doubt that a cautionary approach is taken in relation to the potential benefits of cochlear implantation. The variable response of children to implantation and the lack of the ability to predict the likelihood of 'success' is emphasied repeatedly throughout the process. The term 'success' is also problematised from a gold standard ability to converse with strangers on the telephone to access to environmental sound. This information is provided alongside the catalogue of potential side-effects and risks of surgery and long term restrictions on certain types of activities (scuba diving, rugby, contact sports etc.). This said, we were not given information specifically about or from the Deaf community about the impact that our decision would have on our son's ability to be a member of the Deaf community and the impact of cochlear implantation and potential oral language development on that membership. There is some evidence that parents who have contact with the Deaf community during the decision making process are more aware of the need to position themselves within a well established and fiercely fought debate (Hyde et al. 2010)

Had we made those contacts and been given that information would it have made any difference? Our son is profoundly deaf. He has two cochlear implants, is developing age appropriate oral/aural language skills and attends a mainstream primary school with a statement of special educational needs. Despite his cochlear implants and spoken language he remains deaf and always will be. We, as a family, are in the process of learning British Sign Language to use alongside spoken English both for when he is not wearing his implants or is unable to hear sufficiently (ie. in background noise) and because we believe it is important that he has access to British Sign Language as a deaf person. We have adopted the approach advocated by Perier (cited in Vermeulen, 2007) who suggested that deaf children be given access to both oral/aural and signed language to enable them to make their own choice when old enough to do so. This seems an entirely reasonable stance maximising the opportunities available. To suggest, however, that we are depriving the Deaf community of a future member by giving our son the chance to develop oral/aural language and that we should put the need to secure the future of the Deaf community before the need to maximise the opportunities available to our son seems less reasonable. Our position is not one held in ignorance. We are well aware that cochlear implants do not give our son normal hearing. We are also aware that he works considerably harder that his hearing peers to access sound and communicate using oral/aural language. Whether he chooses to continue with oral/aural language, to use BSL and or to use a combination of the two, at least we have tried to give him the best foundations from which to make that decision.

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End-of-life Care in China: Ecology of Hope

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ABSTRACT

In this thesis I explore the current end-of-life care provision as experienced by older people with advanced cancer in three distinct care settings in Yunnan China: a hospice, an inpatient palliative care ward and a self-help organisation. In particular, I focus on the role of "hope" at the end of life, hope having emerged as a significant aspect of participant's experiences. I took a "multiple-embedded case study" approach, employing mainly qualitative interviewing and observation to capture the richness and complexity of the experience of end-of-life care in different settings.

The findings show that mainstream health care for advanced cancer in China focused on curative western medicine and failed to alleviate prevalent pain and symptoms. Specialised palliative/end-of-life care services adapted from the western palliative care model contributed mainly to relieving cancer pain and symptoms. "Total care for the whole person" – the core of the palliative care philosophy, was an aggregate of the resources located in the family, health care and the broader sociocultural environment.

The study revealed the nature of hope as essentially affirming life in all circumstances and as situated and fostered in a "hierarchical social and cultural ecology of hope" (Feudtner 2005, p. S23) comprising an individual, his or her family, care providers and other physical, social and cultural elements. The fostering of hope, as a resource at the end of life, has implications for improving care and support at multiple levels – personal, interpersonal and social and cultural.

Hence, it is suitable to take the public health approach proposed by Kellehear (2005) to advance palliative care development in China because it endorses a compassionate approach to death and dying and loss and proposes that care for people at the end of life is a fundamental responsibility of not just health professionals, but also communities, governments and societies.

Growing up with HIV: Exploring the experiences of the first generation of young people perinatally infected in the UK

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ABSTRACT

This thesis explores the experiences of young people perinatally infected with HIV in the UK. Although advances in medical treatment have made a major difference to the life expectancy of these young people this may not be matched by their 'lived experience' insofar as they face the consequences of a stigmatised disease as well as an uncertain future. This is the first study to critically analyse young peoples' accounts of growing up with HIV in the UK. This thesis considers the experiences of twenty-eight young people between the ages of fifteen and twenty-four recruited from a London hospital. Drawing on Bury's (1982) concept of 'biographical disruption' and the concept of 'critical moments' (Thomson et al. 2002), it explores how HIV affects a young person's biography.

Findings from the study demonstrate that a diagnosis of HIV disrupts biography and this experience is interspersed by 'critical moments' that serve to bring into sharp relief difference and forces young people to continually re-evaluate and make sense of being HIV positive. Young people make sense of disruption in order to construct and maintain a new identity as they become adults; this process is influenced by the stigma attached to HIV as well as by the disease trajectory. They use a range of strategies to adjust to and manage living with a stigmatised identity. This study raises important questions about the impact of HIV on young people, their families and their relationships. It demonstrates that most young people learn to 'pass' (Goffman 1963) as uninfected and conceal their HIV status. They withdraw from social relationships which increases their isolation and loneliness and affects their well-being. Findings also reveal that young people report little support to help them manage the impact of HIV. The study also highlights the urgent need for future research focusing on young people with HIV.

Keywords: HIV/AIDS, perinatally infected, born with HIV, young people, biographical disruption, critical moments

The holistic discourse and formalising education of non-medically qualified acupuncturists and homeopaths in England

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ABSTRACT

The overarching aim of this research study is to explore the way that Non Medically Qualified (NMQ) acupuncturists and homeopaths in England, as part of their efforts to professionalise and formalise their educational structures, negotiate holistic concepts that are embedded in their theory, practices and discourses. The thesis is the product of an in-depth, qualitative inquiry. Several data sets were used in this research: (1) Twenty-five in-depth interviews with acupuncturists and homeopaths in London and the South of England, including practitioners who are school principals and lecturers; (2) Participant observation of teaching a research methods unit in a BSc (Hons) Acupuncture in a private school for Chinese medicine; (3) A review of practitioners' professional websites, of professional bodies' educational and practice documents, and of 27 acupuncture and homeopathy course syllabi; and (4) Two non-participant observations of a day in an acupuncture practice and a day in a homeopathy practice.

Crucially, the holistic discourse which is interwoven in acupuncture and homeopathic philosophy, theory and practice, is a dynamic discourse, influenced by political and societal factors surrounding these therapies, as well as by the dynamics within the therapies themselves. This research study demonstrates the way practitioners 'narrow' and 'expand' their holistic narratives and practices according to the challenges that they face during the process of professionalising and formalising their education, as well as in relation to their consumers' expectations. This study suggests that the way by which practitioners often negotiate the tension that exists between increasing formalisation and the unique nature of their expert knowledge, can be described as 'pragmatic holism' through which practitioners try and make gains from the formalisation process, without losing their holistic approach and appeal. Furthermore, the entrance of Higher Education Institutions to the teaching of acupuncture and homeopathy courses seems to have accentuated some of the tensions that are part of the formalisation process, but it may also offer opportunities to increase practitioners' critical reflectivity in relation to their holistic discourses and practices and to expand the scope of their holistic awareness.

Keywords: Holism, professionalism, acupuncture, homeopathy

This is not a law: The transnational politics and protest of legislating an epidemic

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ABSTRACT

HIV/AIDS continues to pose some of the most significant social, political and legislative challenges globally. This project explicates the text-mediated processes by which many HIV-related laws are becoming created transnationally though the use of omnibus HIV model laws. A model law is a particular kind of regulatory text with a set of relations of use. Model laws are designed to be taken, modified and used by stakeholders in the creation of state laws. Because they are already framed in legislative language, model laws are worded in ways that can be expeditiously activated and translated into state law. The problematic of this inquiry arises from the activities of a constellation of legislative actors including human rights lawyers, policy analysts, academics and activists who have worked to critique aspects of the United States Agency for International Development/ Action for West Africa Region (USAID/AWARE) Model Law (2004) and subsequent state laws this text has inspired across West and Central Africa. I argue that mapping the origin and uptake of this omnibus guidance text is optimally achieved through a sustained analytic commentary on the institutional genre of "best practice". Explicating the coordinating function of this textual genre is central to understanding the rapid spread of HIV/AIDS laws across at least 15 countries in West and Central African between 2005-2010. The work processes of legislative creation, challenge and reform under investigation demand an interrogation of complex ruling apparatuses regulated by text, talk and capital relations.

The USAID/AWARE Model Law is rife with contestation: from its name, scope, funding source and process of development, dissemination and domestication to its legislative content and role in protecting or violating women's rights and public health objectives. Many of the policy actors critiquing this USAID-funded initiative have been engaged in the development of alternative HIV-related model laws and the shaping of a global anti-criminalization discourse to respond to the increasing use of criminal law governance strategies to prosecute HIV-related sexual offenses and the rise in new HIV- specific criminal laws in and beyond sub-Saharan Africa. This study maps relations that rule, and makes processes of power understandable in terms of everyday transnational work activities organized by the language of law. My research method is informed by the critical research strategy of institutional ethnography. This complex legislative process was made visible through participant observation, archival research, textual analysis and informant interviews with national and international stakeholders. This has involved research in Canada, the United States, Switzerland, Austria, South Africa and Senegal (2010-2011).

Keywords: HIV/AIDS; legislation; transnational; model law; Africa; institutional ethnography

Enacting Biobanks: Governance as Scientific and Ethical Practice

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ABSTRACT

My PhD is dedicated to the phenomenon called biobanking-the creation, running and usage of assemblages of biological samples and data obtained from donors and patients. My thesis establishes the interconnectedness of notions of ethical governance and the practices that constitute biobanking for bioscientific research. My research connects enactments of biobanking and biological data, concepts or entities with their so-called bioethical concerns. Rather than thinking of biobanks as a priori entities that have an impact or must be managed in a certain way, I pose an epistemological question about what a biobank is and what it represents.

I discuss relevant literature from Science and Technology Studies, anthropology, the natural sciences and social science scholarship about genomics, concerning themes such as classification, social order and biological material and information. I connect to the discussion on governing biobanks a more wide-ranging one about the social and the biological. Alongside theoretical challenges, I present fieldwork from three sites that are involved in biobanking practices and, to varying degrees, in biobanking debate and regulation. I contribute to and challenge current understandings of biobanking and the biosciences in three ways. Firstly, I show how the construction of the categorisation of the social and biological is integral to making sense of governance issues and how this categorisation (re)frames these. Secondly, I reconceptualise biobanking as a practice and place the ethical and the governance within that practice. Thirdly, I query the relationships between people, materials and data within the domain of the "biosciences" that enact biobanking and, therefore its governance. Moreover, I question the status of this "biological" as it intersects with notions of biobanking, again through people, materials and information flows.

To dictate a "better" way of biobanking would attribute essential properties to both biobanking and governance, which my thesis refutes. Yet, it holds important lessons in practice for those governing and ethically ordering biobanks and for academics writing about ELSI of biobanks. I urge authors, scientists and policy-makers to consider their audiences, both in terms of scientific and donor communities and in terms of reaching relevant sites where biobanking "is being done". Participants in activities of and debates about biobanking might miss important sites if they restrict their conceptions of biobanking to semantics, because scientists engage with and conduct biobanking through local practices and might not self-identify as "doing biobanking" according to standardised paradigms.

Instead, I suggest assessing the importance of biobanking as practice on social fabric and on roles within the bioscientific and biomedical sector. For instance, this reduces the likelihood of over- or underestimating the importance of biobanking across different contexts. Some scientists hold a view of biobanking as a domain of practice in its own right that is, however, carried out by a limited set of people defined as "biobankers"; other settings do not self-identify in this way, even though all professionals across the clinical and research domain are involved in the practices of biobanking at the site. Conceptualising biobanking as a practice remains key to these deliberations and it also, finally, urges a focus on how science and

ethics work together to produce certain status quos.

To illustrate these points in contemporary biobanking debate, my thesis creates a juxtaposition between the debate on whether or not results from biobanking research should be returned to biobanking donors (and, if so, which types of results) with the debate on how and whether access to donated samples and data should be granted to other research groups within the bioscientific community. I argue that visions of the biosciences are often shared and propagated between donors and scientists, while donors are also enlisted as virtual allies in the alleged need to develop ethical data-sharing policies within science. On the other hand, biobanking practices that do not share with donors results of the research uphold and are often based on their enactment as a lay audience. Considering the two debates together thus deconstructs any a priori status of donors and of bioscience by questioning the social relations involved between donors and scientists and amongst scientists across various governance challenges for biobanking.

Spirituality in psychotherapy: A hidden dimension. An exploratory study

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ABSTRACT

Many in the caring professions consider spirituality to be a fundamental dimension of human experience and identity. Consequently, some claim that this dimension cannot be ignored in disciplines such as psychotherapy that deals with the human being and with human experience. Moreover, the increase in secularisation and the emphasis on the subjective and the personal in people's experience of spirituality and religion, have led to an increased interest in psychotherapy, counselling and other forms of activities and professions that deal more closely with the personal and subjective. Other themes that connect spirituality and psychotherapy include: spirituality is related to a person's mental health; people make meaning which assumes that they are spiritual beings; and spirituality and psychotherapy both involve enlightenment and meaning-making. For some, spirituality is manifest in psychotherapy either because of spiritual concerns that are raised by clients in the psychotherapeutic process, as a resource, or as a form of pathology. For others, therapy is a spiritual encounter.

The research is a qualitative exploratory study of the experience and perception of the spiritual dimension of psychotherapy of Maltese practitioners. The study was held with two groups of Maltese psychotherapists and clinical and counselling psychologists. Each group attended a series of four focus/study group sessions. Key areas explored include the participants' conception of spirituality and religion and their understanding and experience of the spiritual dimension in counselling and psychotherapy. Broadly, the study focused on the ways in which spirituality may become manifest and express itself in the psychotherapeutic process, the roles and experiences of the therapist and the client regarding spirituality in counselling and psychotherapy and the identification of the factors that may contribute to the spiritual dimension of counselling and psychotherapy.

The findings are presented as two main domains, that of 'understanding spirituality and religion in a postmodern context' and 'spirituality and psychotherapy'. The latter is divided into four themes that are facets of the domain 'spirituality and psychotherapy'. These are a) understanding spirituality and religion, b) the therapeutic relationship as sacred space, c) the being: it is who the therapist is that counts and d) applications in clinical practice. The findings are discussed in relation to the literature and to the Maltese context.

Touching work: a narratively-informed sociological phenomenology of Holistic Massage

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ABSTRACT

This thesis comprises an exploration of the practice of Holistic Massage, working across the sociological areas of complementary and alternative medicines (CAM), body work, emotional labour, sociological phenomenology and narrative inquiry. Holistic Massage is one of a plethora of practices encompassed by the field of CAM. While there has been steadily increasing sociological interest in CAM in recent years, much research has treated this diverse group as relatively homogeneous. This thesis looks at one practice in depth, in order to address issues specific to Holistic Massage - including what 'holism' adds up in to in practice, and the devaluation of knowledge based on touch(ing) - as well as those concerning CAM more broadly. Hence, whilst drawing on existing research on CAM, this research also addresses a lacuna within it via a novel methodology.

The thesis employs the conceptual tool of 'touching work', which brings together the concepts of 'emotional labour' (Hochschild 1983) and 'body work' (Wolkowitz 2006 and others) in a way that draws out relevant aspects of each around the fulcrum of touch, thus accounting for the latter in both its sensory and emotional meanings. In so doing, it also contributes to the recently burgeoning literature on the senses in sociology, and to an embodied sociology more generally. The thesis also draws on sociological phenomenology, in particular the notion of the intersubjective 'stock of knowledge' (Schutz 1963), and the understanding of talk as constitutive of the everyday social world. The overall methodological approach taken - which is outlined fully in the second chapter - brings together phenomenological theory with narrative inquiry, and specifically with the analysis of the form and content of talk. The analysis presented is based around data from loosely-structured interviews with ten women who do Holistic Massage. The interviews were analysed in terms of their overall shape and distinctive features (Chapter Three) and, in subsequent chapters, with respect to both what was said and how it was said. This analysis examines the constitution of a Holistic Massage stock of knowledge (Chapter Four) and how the practice is bounded (Chapter Five), and concludes in Chapter Six by taking a step back from the detail of the data to look at what can be known from it about Holistic Massage and touching work.

Piecing together the constitution by practitioners of a stock of professional Holistic Massage knowledge makes a significant contribution to the sociology of CAM, and thus to medical sociology more broadly. Also, by uniting phenomenological sociology and narrative inquiry, it provides a novel perspective on a form of work which is part of a small but significant contemporary occupational field in the UK. In particular, it draws out the multiple aspects of touch which can in fact be known and articulated through talk and challenges ideas about the supposedly ineffable character of touch. In this regard, it points to similarities between how practitioners talk about this and the Foucauldian challenge to the 'repressive hypothesis', which sees people as in fact talking readily and in detail about matters where they claim silence prevails.

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Caring towards death: A phenomenological inquiry into the process of becoming and being a hospice nurse

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ABSTRACT

This thesis seeks to illuminate the question of why nurses choose to work with dying patients, with the meanings nurses attribute to their experiences forming the essential material of the study. Adopting a hermeneutical phenomenological perspective, the study involved semi-structured interviews with 30 nurses working in English hospices. The results provide evidence of the ways in which narrative and experience inform one another in an active process of occupational identity formation. Through a search for congruence between ideals and working environment, the nurses had arrived at a point of equilibrium, having identified in hospice a setting in which their nursing ideals could be implemented.

A marked feature of the nurses' accounts was 'dichotomous perception' of the nursing care provided in NHS settings and that provided in hospices, with the dimensions of these contrasts representing ideals embodied in nurse education. Aspects of hospice nursing particularly valued by the nurses were opportunities to provide 'good' nursing care, 'hands-on' nursing, holistic patient care, 'being there' for patients and availability of time.

In the face of conflict between discourses of nursing care and management discourses focused on cost-effectiveness, these nurses remained uncompromising in their desire to provide 'good' patient care and were, in Maben et al's terms, "sustained idealists". However, the equilibrium they had achieved was perceived by some to be under threat, with financial restrictions and other factors challenging the nurses' identity as hospice nurses.

In developing an understanding of the way in which individuals set their personal narratives in the context of societal factors and engage their dynamic selves in ongoing conversation with themselves and others, the thesis illustrates that, as individuals, we can only make sense of our selves by taking account of the world around us.

Keywords: Hospice, palliative care, nursing, death and dying

Technological Innovation and Change of Nursing Work in an Emergency Department

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ABSTRACT

This thesis evolves around the identification and analysis of the particular sociotechnical factors and conditions that facilitate the implementation of new information and communication technologies (ICT) in complex clinical settings.

Today most national health systems around the world link the need for best healthcare provision with the overall efficiency of their institutions. Such orientations undoubtedly require outcomes linked to ICTs so as to assign them with criteria and measures of success. On the other hand, implementations of such technologies in healthcare organisations, particularly under the Connecting for Health (CfH) IT programme, have not been equally successful. As science and technology studies (STS) scholarship shows, these technologies, despite their technical robustness, do not guarantee successful implementations. It is rather the intertwining of people, machines and spaces at the local setting that determines the fate of the new system.

The four-hour waiting target (now a standard of hospital performance) for patients attending an Accident & Emergency Department (A&E) has undoubtedly become the most important catalyst of effective change towards a "whole system" approach in the provision of unscheduled care. This is, partially, because waiting times in A&Es have been acknowledged as one of the most prominent causes of dissatisfaction for patients interacting with the National Health Service (NHS). From the mid-1990s, Conservative and Labour, governments in the UK have developed and implemented a series of reform programmes to address this issue. After a long series of negotiations, which were intensified at the dawn of the new century, the Department of Health (DH), in accordance with the recommendations of relevant emergency clinical bodies and patient advocacy groups, stabilised, in 2004, the target (now a standard of hospital performance) to 98% of patients attending A&Es to be treated and admitted or discharged within four hours. During that time the DH also released a report with key recommendations on building layouts for these hospital departments in order to positively influence efficient patient care by appropriating circulation spaces for patients, clinicians and visitors.

This thesis is a case study of the implementation of a clinical information system for patient registration and tracking in the busy emergency department of a large Acute Care University Trust in East Midlands, UK. It explores the complexity of relations and subsequent negotiations between these heterogeneous elements during the formation of a new practice ordering for nursing work.

For this, I draw on the work of actor-network theory (ANT), firstly, within the broad field of geography. I conceptualise space and time as invaluable non-human entities that need to be enrolled and converged at the local level in order for the inhabitants (clinicians, administrators, managers) and the visitors (patients and their carers) of this temporal network to enact prescribed movements, interactions, communications and relationships. From there,

this thesis examines the way the above national policies (i.e. waiting time targets, built environment design) have come to facilitate the introduction, and subsequent stabilisation, of a clinical ICT in the local clinical setting.

Based on the findings from the analysis of 30 semi-structured interviews with nurses, change managers, system administrators and emergency department assistants as well as of relevant policy documents, internal reports, building blueprints and implementation studies, I argue that the re-engineering of healthcare practice with the diffusion of a new technology is not a fixed and linear process, but more of an interplay of various fluctuant, performative and co-constitutive technical and social factors. In particular, I first show that the DH strategically attempted at ordering the A&E towards specific outcomes of performativity by formalising procedures, interactions and generally the behaviours of these peripheral networks. Rooms and corridors were redesigned and timestamps are now being applied to every process so as to effect a new spatio-temporality in the planned circulation of patients and hospital staff. As a result, groups of users are being integrated or segregated according to particular (and rationalistic) conceptions of patient flows.

For the above purposes, the specific technology under examination (EDIS) arrives in the A&E as an efficient technological solution to a given waiting time problem. While issues of computer competence and interaction with complex technologies remained a concern for nursing staff during the implementation phase, these were substantially downgraded in the face of the new rigid policy. The technology was gradually translated and transformed into an invaluable ally. Conversely, success included not only the appropriate use of the system, but also the users' high dependence on it and finally the network's ability to act as a platform for continual, technologically mediated, reformation of its practices under specific strategic policies.

Through an ANT conceptualisation, the thesis concludes by arguing that despite the various negotiations that take part between the centre of calculation (DH) and the local setting (A&E) offering, to the latter, some room for manoeuvre and discretion, in the end, the former is constantly enhancing its instrumental and obligatory passage role in shaping local action. It does this by strategically organising the opening of the black-box of its constituted healthcare institutions through their enrolment, re-skilling and, after that, their mobilisation towards specific process outcomes.

Book Review
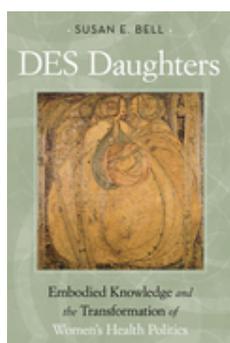
Bell, S. E.

DES Daughters: Embodied Knowledge and the Transformation of Women's Health Politics

Philadelphia: Temple University Press, 2009, paperback

ISBN: 978-1592139194

232pp

Reviewer: John MacArtney

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Susan Bell's book DES Daughters draws on two decades of research into the lives of women affected by 'DES' (diethylstilbestrol) since the 1970s. DES is a synthetic estrogen that was used from the 1940s until the 1970s to prevent miscarriages and promote healthy pregnancies. However, in 1971 DES was discovered to be the 'first transplacental carcinogen' when it was found to affect the reproductive organs of the daughters, reducing their chances of conception and increasing their possibility of developing a rare type of vaginal cancer. This instigated the development of DES activist networks across the USA, who lobbied for DES related funding, research and legislation, and who are still active today.

Bell's analysis combines three analytical frameworks. The first, 'feminist health scholarship', highlights the changes in the ways feminists have understood and analysed power and knowledge since the 1970s; moving from 'sovereign' conceptualisations, through to Foucault's description of exercising 'new regimes' of power, to Bell's analysis that seeks to go beyond 'old' and 'new' to show the complex and multilayered relations in healthcare.

Secondly, Bell describes the importance of 'embodied health movements'. Bell's book describes key moments in the formation of the DES movement, as they used their direct experiences of illness to critique the medical and scientific systems, instigate funding and legislation, and challenged the political economy and traditional assumptions. An 'inextricable part' of this was the relationship both activists and DES daughters had with science and medicine. Bell shows how this embodied health movement used their embodied experiences of illness to gain a seat at the scientific table.

Thirdly, Bell provides a narrative analysis of interviews with DES daughters, conducted from 1982 to 1995, as well as other textual and visual sources. In doing so Bell aims to show how DES daughters reflect, resist and transform the discourses that circulate around and through their experiences. To do this Bell emphasises the multiple narratives present in each story and across contexts. She argues that it is then possible to see how individual choices rework and refigure the discourses at hand to create new pathways through old narratives.

In chapter one Bell sets the context for understanding the stories of DES daughters. DES history is part of what has been described as the "hormonalisation" of women (Oudshoorn, 1994; cited in Bell, p15). Bell maps the multiple strands of activism and regimes of practice

from the early responses to DES, through the initial realisation of DES's carcinogenic effects to the emergence of an embodied health movement.

In chapter two Bell focuses on the narratives of those DES daughters who were diagnosed with cancer and how they assumed the identity of a DES daughter and, in turn, how this developing identity and growing knowledge of DES affected their negotiations with medical practitioners. One of the strengths of Bell's book is the empirical work she does to locate each narrative in the cultures surrounding them and showing how each DES daughter negotiated her way through these. Furthermore she is able to show how their, sometimes deficient, responses contributed to the transformation of relationships of knowledge and power in the care of DES daughters.

In chapter three Bell explores the 'special irony' of those DES daughters who have suffered from infertility and pregnancy loss, due to their exposure to DES; a treatment that was supposed to enhance reproduction. On the one hand Bell uses these narratives to highlight how, despite being the 'embodied failure' of reproductive technologies, many DES daughters pursue motherhood through risky new reproductive technologies. In doing so Bell finds a power in their voice to legitimise the knowledge they produce that both informs and contests the medical view. But on the other hand, Bell uses this to explore the social expectations and bodily experiences of DES daughters, in particular the expectation of 'seamless movement' from conception to birth. In turn she considers how DES has made many 'counterdiscourses' possible, such as 'when enough [medical intervention] is enough'.

Chapter four continues this theme of analysis to show how limits of medicine enabled DES daughters to speak authoritatively about their bodies. Bell shows how, in reconstructing the knowledge about their bodies, the DES daughters were able to contest medical sovereignty. Nonetheless, as chapter five shows, knowledge and power over the body remained a co-constituted project. DES daughters relied on their doctors regimes and practices of knowledge, but were able to reposition their 'subjugated knowledge' (Foucault, 1978; cited in Bell, p120) through their embodied activism at the scientific table so that, Bell argues, there was now "multiple and shifting voices in the production of knowledge" (p13).

In the final chapter Bell draws all of the above together through an analysis of Judith Helfand's (1996) autobiographical documentary A Healthy Baby Girl. Bell shows how multilayered narratives, including previously formed DES narratives, biomedicalise Helfand's body and the life. However, Bell also explores how Helfand is able to reform these narratives and other resist cultural imperatives, such as the demand to become a mother, through engaging in 'counternarratives' that were then emerging in the DES activist milieu.

Two key themes therefore emerge from Bell's analysis, the importance of multilayered narratives in the constitution of knowledge and the concomitant 'circulation' of the relations of power. If there were a critique of Bell's analysis it would be this application of Foucault's concepts, which too often feel juxtaposed to the excellent empirical work, rather than being emergent from it. Thankfully, this does not significantly detract from Bell's excellent exploration of how DES daughters' multilayered embodied knowledges challenged, resisted and reconfigured formal scientific and medical knowledge, across three decades and in multiple locations.

Book Review

Lloyd, L.

Health and Care in Ageing Societies: A new international approach

Policy Press, 2012, paperback

ISBN: 9781861349187

176pp

Reviewer: Pamela Pitman Brown

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The book is one of the newer titles in the 'Ageing and the Lifecourse' book series edited by Judith Phillips. The series provides gerontology books that construct ageing from a socio-cultural standpoint as opposed to a medically based perspective. The book offers the social and globalized standpoint of health, care, ageing, ethics, morality, and policy, relaying to the reader how these aforementioned standpoints are inexorably linked and difficult to extricate

The book's theoretical framework, feminist ethics of care, reflects Carol Gilligan's 1982 dissertation and book, In a Different Voice. While at Harvard, Gilligan's work juxtaposed her mentor, Kohlberg, and his moral development stages. She considered the ways women operated under the Kohlbergian moral development ladder and questioned if the Kohlbergian concepts were universal and gender neutral, additionally questioning the differences in the language of men (ethic of justice) and of women (ethic of care). In chapter one, Lloyd describes how the feminist ethics of care principles converge and proceeds to explain how the ethics of care correlates to the topics of ageing, health, policies, and care, from a local to a global level.

Chapter two addresses ageing and health from a demographic and epidemiologic perspective, highlighting life expectancy, mortality rates, and causes of death. Additionally, Lloyd addresses levels of dependency fluctuations throughout the lifecourse, by bringing in value of life perceptions, and, how this value is often explicitly set forth within political priorities and resource allocations. The 'double burden' of morbidity is discussed in terms of the rapidly ageing population and socio-economic climates, which influence a 'double-burden' conundrum, and explaining the complexing nuances of the epidemiologic transition's 'protracted polarized model.' Following the intent of the text from a sociological standpoint, chapter two also presents information concerning inequalities based on gender and on the social determinants of health.

Chapter three is based on the interpretations of health and care, from a sociological and epidemiological perspective. Lloyd delves further into the explanation of feminist ethics of care (p. 38), enlightening the reader to other feminist care works by authors such as Kittay, Tronto, and Held. Additionally, Lloyd gives a much more detailed expose on approaching health and care from a lifecourse perspective (p. 41). She also addresses Laslett's third age theory in much more depth pertinent to socio-economic health determinants.

Lloyd acknowledges within chapter four there is no linear process through which policies flow in order to be created, researched, and implemented, but that the process is a 'patchwork of actions and non-actions, a process of negotiation' (p. 67). It is a witch's brew of distributive justice, entitlement, eligibility, morals, values, and ethics. Throw into the amalgamation globalisation, ideologies, agendas, priorities, power, and of course, money. Lloyd points out the socio-economic inequalities globally, including the banking crises, and moves the discussion to power consolidated within interests groups, pointing out laissez-faire, fragmented, or constricted healthcare systems.

Chapters five, six, and seven should be considered together as each one addresses various aspects of health and care, following a health promotion model or 'tertiary prevention model' premise. The chapters correlate with each of the levels: primary/prevention and promotion (five), secondary/restorative (six), tertiary/maintenance (seven). Each of the chapters examines the policy actions and implications within the context of aging. Lloyd additionally reminds the reader that the three levels within the 'tertiary prevention model' should not be considered as separate goals but interacting, and each one is also considered within the ethic of care paradigm.

While presenting a solidly historical background of the ethic of care, one needs familiarisation within the capacious feminist historical paradigmatic traditions prior to teaching with this book. One should also be well-versed in numerous aspects of epidemiology, demography, inequality, and above all, the infusion and influence of the lifecourse. Although extremely informative and very well written, as a professor I would suggest a perusal of chapter three might be a good precursor to reading chapter 1, particularly if a student is coming in with a paucity of knowledge on feminist ethics of care or a background in lifecourse/gerontology. I found chapter four to be the most discussion provoking, visualising classroom conversations over scarcity of resources, death panels, universal, capitalistic, and socialistic health care approaches. As a professor teaching health promotion and aging, I was ecstatic to see how Lloyd utilised used the last three chapters to focus on the 'tertiary prevention model' and viewed through the lens of aging, juxtapositioning each level with the aging process. I would absolutely use this book within a graduate-level health and aging policy course. I am inclined to think that it would be more problematic for undergraduates, as outside readings maybe required for full understanding of the interconnections.

Book Review
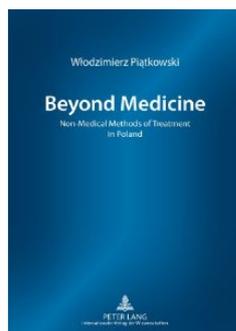
Piątkowski, W.

Beyond Medicine. Non-Medical Methods of Treatment In Poland

Frankfurt, Peter Lang, 2012, paperback

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307pp

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Non-medical treatment methods are rarely the subject of systematic and comprehensive study. However the research interest in that area is growing now that health is no any longer considered simply as the absence of illness - but rather as a state of wellbeing The book 'Beyond Medicine. Non-Medical Methods of Treatment In Poland' written by the Polish medical sociologist Włodzimierz Piątkowski is the first monograph in Poland dealing with this topic that has been translated into English. It consists of three parts. The first section, 'Non-Medical Healing Systems as Sociological Phenomenon' offers a comprehensive analysis of the phenomenon. Here the author discusses the background of the conflict between official main stream medicine and non-medical methods as well as the legal and ethical aspects of non-medical treatment approaches. As in other countries, Polish medical doctors and healers have been fighting ethical and legal battles over the boundaries of medicine and these are still not resolved. In such battles the patient is often forgotten. Piątkowski argues that the right of patients to choose treatment methods and therapists versus the right of the patient to receive proper reliable information on treatment can be resolved only by providing him/her with the results of objective scientific studies.

We live in times of creative, self-confident and educated patients who are ready to take initiative and control in health matters e.g. by use of the Internet. At the same time, the average consumer of medical or non-medical services has to navigate between, on the one hand, information about iatrogenic effects of biomedicine and, on the other hand, anecdotes about miraculous effects of non-medical methods, presented mainly by healers themselves.

Piątkowski provides an excellent review of sociological research on non-medical treatment in Poland, as well as outlining the state of the art in sociological research on Complementary and Alternative Medicine (CAM) in Europe and North America. This short, but important, overview of research findings covers medical anthropology, the history of medicine and clinical medicine. One needs to remember that we are dealing with a multidimensional and multidisciplinary phenomenon and one also has to keep in mind the hegemony of evidence-based medicine particularly in Europe and North America. It would have been wonderful had this part of the book been complemented by an overview of studies conducted in other parts of the world: such as Asia, South America or Africa.

The second part of the book 'Polish Folk Medical Systems and Self-treatment - Continuity and Change.' provides a very interesting overview of Polish socio-medical studies on folk

medicine, also from a historical perspective. However I would argue that it is much too early to talk about a non-medical treatment system. Can we really call those non-medical services a system, do we know enough of its inner structure and organization? Despite the growing popularity of non-medical treatment in Poland there is a scarcity of research into this phenomenon. Piątkowski attempts to illuminate the social context in which traditional folk medicine and self-treatment functioned during the early twentieth century. This part of the book includes a chapter on women and their traditional role as domestic therapists and as folk practitioners. However, the research review presented in that chapter - especially the part on determinants of illness behaviour - should be read with caution. Although Pi_tkowski purports to provide a historical perspective, the paucity of recent studies on this topic gives the reader the potentially misleading impression that almost nothing has changed during last 100 years and that the results from the 1940s or 1960s still somehow represent the state of the art in this field. Unfortunately the most powerful quotations in that chapter come from studies conducted before World War II.

The third part of the book 'Therapies of modern healers. Specificity, contexts and interpretations' partially repeats the arguments presented earlier in the book. In my opinion., the results of the research conducted in Poland presented here, should not be compared to other European studies without a more detailed description of their research designs, the scope of methods covered and sample definitions - to mention just a few of the criteria for sound comparative research. However this part of the book also provides an instructive case study of the Kashpirovsky phenomenon: the great popularity of Anatoly Mikhailovich Kashpirovsky - a Russian psychotherapist of Ukrainian origin, hypnotist and controversial psychic healer. Piątkowski describes the scale and the sources of early 1990s Polish public interest in Kashpirovsky method (tele-therapy) and also in the healer himself. He draws here on his analysis of more than one thousand letters sent by TV-viewers to the Polish TV company, addressed to the healer.

All in all, 'Beyond Medicine. Non-Medical Methods of Treatment In Poland.' is a welcome and important contribution to the sociological literature on non-medical treatment methods and deserves a wide readership, both outside and within medical sociology.

The most striking message from the book is traditional medicine's neglect and ignorance of the very real and very important emotional needs of its patients. Those needs are being answered by various healers who are ready to a build warmer, deeper and closer rapport with their patients and give them more words, more time and more empathy. Piątkowski writes that "unconventional healing requires the patient's active cooperation during the treatment process, joint responsibility for therapy, recognition of joint definitions of health and illness, and close patient-healer relationships" (p.107). To be effective, we would actually expect of every treatment process, regardless of its framework, that it meet these conditions - easy to say; hard to meet in practice.

Current Online First Articles: A Digest

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This new feature for MSo provides a personal selection of articles shortly to be published in a range of relevant journals – *Health; Qualitative Health Research (QHR); Social Science and Medicine (SSM); and Sociology of Health & Illness (SHI).* The spread of current articles certainly reflects the breadth of medical sociology (both in relation to topics studied and the methods employed) and its international reach.

At the quantitative end of the spectrum, Semyonov, Lewin-Epstein & Maskileyson have analysed data from 16 countries in order to explore the "wealth-health" gradient. "Where wealth matters more for health: the wealth-health gradient in 16 countries" (*SSM*). They found that, although the average health of national populations rises as economic resources increase, the tie between wealth and health does not weaken. However, a more equitable distribution of resources does not improve health at a population level, but the link between wealth and health is weakened.

In SHI there is another quantitative paper on "Suicide rates and socioeconomic factors in Eastern European countries after the collapse of the Soviet Union" by Kõlves, Milner & Värnik. The former USSR kept its suicide rates secret and unpublished until the transition period of the 1990s when reporting suggested rates were increasing. The number of GPs in the population was used as a proxy of social integration and regulation at a wider societal level. The study shows that social integration and regulation have impacted on suicide rates in Eastern Europe since the collapse of the former Soviet Union. While the suicide rates of the Baltic and Slavic republics of the former Soviet Union have decreased since the mid-1990s, this region continues to have the highest suicide rates in the world, especially of men. The authors claim that having more educated doctors would increase the resources available to recognise and treat potential suicides.

Still addressing the topic of health inequalities, but focusing on the Norwegian experience Kravdal *(SSM)* addresses poorer cancer survival amongst the unmarried and examines the role played by co-morbidities.

Drawing on data from an ethnographic study, Spencer *(Health)* takes a critical look at the notion of empowerment in relation to young people and health and offers a new conceptual framework for understanding empowerment as a generative concept. She explains that these forms of empowerment capture and synthesize individual, structural and ideological elements of power that differentially, and sometimes inconsistently, shape the possibilities for young people.

Another paper which looks at the relationship between conceptualization and behaviour is featured on the *Health* website. This is by Baart & Widdershoven and is entitled "Bipolar disorder: idioms of susceptibility and disease and the role of 'genes' in illness explanations". This reports on a focus group study which identified two contrasting orientations amongst members of the Dutch Association for People with Bipolar Disorder. In particular the paper explores the implications of these two approaches for self-management.

 "Co-construction of chronic illness narratives by older stroke survivors and their spouses" by Radcliffe, Lowton & Morgan *(SHI)* also explores the creation of meaning – in this case utilizing joint interviews with couples. Glenn, McGannon & Spence *(QHR)* have carried out an analysis of media representations of weight-loss surgery, using an eclectic approach to discourse analysis. This research relates to coverage of a specific Canadian bariatric clinic. In particular the paper examines the role of gendered and biomedical discourses.

Both *SSM* and *Health* feature articles about ADHD. Edwards & Howlett (*SSM*) explore the dynamics of knowledge production about ADHD in Ireland, and focus on how parents of children with ADHD are intervening in knowledge creation regarding the effectiveness of different treatments. The paper draws on interviews with parents and professionals active in this arena. In *Health* Frigerio & Montali compare the ADHD discourses of Italian mental health professionals, teachers and parents. Their approach integrates positioning theory (from CA), dialogical thinking and discourse analysis to study stakeholders' "reflexive and interactive positioning in terms of the attribution of rights, duties, responsibilities and power issues." The authors conclude that the loop of mutual refusal to recognize the rights and agency of others may have concrete negative implications for children, since it may prevent effective collaboration.

The last two papers selected both address ethical issues. Drawing on observations and interviews with one UK-based group of neuroscientists, Brosnan, Cribb, Wainwright and Williams *(SHI))* explore what ethics means for these researchers, active both in the lab oratory and in the clinic. The paper articulates and explores the notion of 'tangible ethics' as enacted in everyday practice where the scientists' discursive distinctions between right and wrong could be challenged.

The final paper "Bioethics in practice: addressing ethically sensitive requests in a Dutch fertility clinic" reports on observations carried out at multidisciplinary ethics meetings (as part of a bigger ethnographic study) by Gerrits, Reis, Braat, Kremer & Hardon *(SSM).* This afforded the opportunity to focus on real life cases, rather than having to rely on hypothetical vignettes. Although health professionals' autonomy might be invoked occasionally to withhold treatment, the authors highlight the uncertainties involved and show that, in some cases, patient autonomy is appealed to with couples being left to weigh up risks.

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