

Medical Sociology online

A Journal of the BSA MedSoc Group

The logo for Medical Sociology online (MSO) features the letters 'MSO' in a bold, black, sans-serif font. The letters are positioned in front of a stylized, glowing orange sphere that has a gradient and a shadow, giving it a three-dimensional appearance. The background of the logo is a solid orange color.

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Joyce Cavaye

Editorial

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Welcome to this issue of Medical Sociology online, the second of three planned for 2013. The content in this issue is, as usual, wide-ranging and includes an update on the MSo/MSN archive, peer-reviewed articles, commentaries, abstracts of recently awarded PhDs, book reviews and our newest feature - a digest of recent online articles.

Trawling through the archive has given us a fascinating glimpse of the challenges facing medical sociologists from the early 1970s when the first newsletter was produced. The most innovative technology that our former colleagues had to help them produce the newsletter was perhaps an electric typewriter; they still had to rely on the good old snail mail to reach their 350 readers whereas today, you like another 12,500 visitors, can access the journal with a click of a mouse or a swipe of your figure.

From the archive we have selected two papers - by Jon Gabe and Barbara Katz Rothman - to reproduce because we felt that they were as relevant today as when they were originally published almost two decades ago. These articles, while dealing with very different topics, both touch on the same issue of how scientific information is conveyed to laypeople and the consequences of that. Gabe's paper uses the moral panic surrounding an outbreak of necrotising fasciitis to highlight the way in which 'risk' to health is now a major issue for lay people, experts, journalists and governments. Katz Rothman's paper based on the views of midwives, focuses on how dominant scientific discourse and knowledge about human genetics pose risks to expectant mothers.

In the first peer-reviewed article by Ferguson and colleagues, Gabe's concept of a 'risk industry' is implicitly observed in its discussion of risk management strategies. This paper empirically examines an often unreported but important influence on human error, fatigue. The causes of fatigue from personal, institutional and workplace cultural perspectives are established. The corresponding strategies used to minimise any potential risk offer many interesting insights that could enable safety and well-being at work.

The next article by Acadia also addresses risk when noting the continued experience of health inequalities within Arctic populations. Here the focus is on how a conceptual model can illustrate links between social networks and health across social, cultural, and behavioural structures. This model, Acadia argues, draws attention to the complex factors that influence the generation of community and social resources, which in turn could improve health outcomes for this diverse population.

Our final article, by Ellis and O'Donnell, is based on 3 papers presented at 2012's Critical Issues in Irish Society Network conference 'Health in Crisis', and looks at the extent to which Ireland is moving towards addressing the broad social structures enabling and constraining health and wellbeing in the country.

The commentary in this issue presents a stark warning to researchers and practitioners who neglect to listen to the voices of people with autism. Understanding autism requires participatory, inclusive research designs; a call that many will agree with.

We have a report about the recent One-day Meeting organised by the BSA Medical Sociology Study Group & Social Science and Medicine, to celebrate Professor Dame Sally

Macintyre's contribution to the research field of health inequalities, written by an early career researcher Sylvia Scalibrini. We are delighted to be able to publish this for two reasons; firstly as a record of an event which many will have been unable to attend; and secondly, one of the aims of MSo is to give new authors the opportunity to be published. We would welcome more pieces like this for future issues.

We continue to receive abstracts of recently awarded PhDs relevant to our field and four appear in this issue. We offer our congratulations on their successful completion and welcome these scholars into the medical sociology community. We look forward to including more abstracts in forthcoming issues and urge all supervisors to remind their students of this opportunity to share their success.

We have two book reviews in this issue and would like to encourage readers and post-graduate students in particular, to consider submitting a short review for Medical Sociology online.

The new feature introduced in the previous issue, provided a digest of current articles available online prior to publication. We have had some very favourable feedback on this and now intend to make it a regular feature of MSo.

Finally, we would like to express our thanks to colleagues, contributors and the MedSoc Group Committee for their support.

Looking Back – An Update: Extending the MedSoc Archive

Charlie Cavaye

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Our appeal, in the last issue of Medical Sociology online, for help in finding the missing editions of Medical Sociology News to complete the archive kindly loaned to us by Professor Barbara Harrison, elicited an immediate response from Professor Robert Dingwall of Nottingham Trent University. Professor Dingwall was able to give us copies of 14 of the 17 missing issues, including all of Volume 1 which we had not expected to find.

The arduous task of scanning each and every page of these back numbers is now underway and the Medical Sociology online website now has all the issues bar one, going back to Volume 16 Issue 1 (published in December 1990), available for reading (www.medsoconline.org/msoarchive/archive.html). The scanned pages have also been processed using Optical Character Recognition (OCR) software to enable them to be searched using the facility on the website. It should be noted however, that for many of the issues (prior to Volume 26 Number 1), the print quality of the originals is less than perfect and we apologise if parts are difficult to read or the OCR software has been unable to recognise words.

The Medical Sociology online (MSo) editorial team have been charged with looking through each of the back issues, to identify articles which may be of interest to the MedSoc community today, with the intent that, over our next few issues, we re-publish them. For this issue we have selected an article from Volume 20 Issue 3, published in August 1995, by respected author Jon Gabe, entitled "Health, Medicine And Risk: The Need For A Sociological Approach".

We have also selected a piece, first published in December 1996 (Vol. 22, Iss. 1), by Barbara Katz Rothman. It is a paper presented to the British Medical Sociology Association, in Edinburgh, in 1996 entitled "Medical Sociology Confronts the Human Genome". Professor Katz Rothman has kindly provided MSo with her thoughts on it in 2013.

There is something sad about reading this piece 17 years later. They never did reach that moon they were after. Science is not able to predict everything there is to a person from the genome - the holy grail of the genome rather crumbled beneath our hands and it turns out we really are not just our genome writ large. The hunt for the essential self now seems to be shifting to the neurosciences. Perhaps that map will lead us to the soul? Or who knows where they will be looking next.

But the technologies of prediction, the painful and sad consequences of 'spoiling the pregnancy,' the irrational expectations of 'safety,' are all the more with us. Connectedness continues to be devalued with devastating consequences to the pregnant women involved. Fetuses are so far removed conceptually from pregnancy that outsourcing has come to this too - with the genome tested, the ultrasound up on Facebook, the pregnancy can be moved off to India or wherever labor is cheap.

We confronted the genome, are getting what information is to be gotten - and still seeking the wisdom.

Barbara Katz Rothman, May 2013

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We hope that our work to extend the archive is of use to the students, researchers and academics working in the field today and that you agree with our selection of articles to reprint. If you find - or are aware of - any papers in the archive which you think we should republish, please let us know and the editorial team will consider your suggestions for a future issue.

Finally, as noted in the opening paragraph, we are still missing three issues of MSN and we would be extremely grateful to anyone who can loan us a copy of any of them to complete the archive; details are below.

Missing Issues

2.3 Was it ever published? (The cover of Issue 2.2 shows '2.3' but the editorial states 2.2)

7.3 Late 1980?

23.3 August 1997?

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.

Medical Sociology Confronts the Human Genome

Paper presented to the British Medical Sociology Association,
Edinburgh, September 20th, 1996

Barbara Katz Rothman, Ph.D.

Professor of Sociology
City University of New York

This article originally appeared in Medical Sociology News Volume 22 Issue 1, published in December 1996.

I cannot seem to let go of birth, of the midwives, of what they have taught me of birth - and from that of death, illness and of life. Birth is a touchstone for me, a grounding, the place I stand.

So when I came to the study of genetics, of the increasing "geneticization" of everything, it was from the perspective of birth. First, and most simply, that means I looked at what this new genetics means for birth, how this will - and does - shape the experience of women who bear children.

More fundamentally though, it is from an understanding of what birth means that I see genetics.

Genetics offers itself as a science - as such, it presents itself as a neutral exploration of facts, an uncovering of a previously ordered world. And yet, we know quite well genetics comes from somewhere, stands somewhere, and sees the world from that place.

That place, that larger hegemony in which genetics grows, is the world view of late twentieth century Western thinking. I can only in the limited space available here, 'shorthand' this, but there are a few key elements of that world view to which I'd like to draw your attention. First is that it is a profoundly individualizing standpoint: a perspective that assumes the isolated individual as the Starting point. Just as in sociology itself, when we say that the essential question is how the social comes to be, how people come together, we accept the assumption that in our essence we stand as individuals, apart.

This is not the way the world looks for one who is grounded in birth as a reality: we grow in and from other people's bodies. That is not an abstraction or a metaphor, but a deeply physical reality. What we have done in the contemporary world is made birth and connectedness the abstraction, and the isolated individual the reality, the essential truth. Oddly, at the same time and place that I address the British Medical Sociology Association the Society for the Protection of the Unborn Child meets. If you look at their literature, their strange and disturbing photographs of fetuses, you can see the point that I am making: ultrasound imaging has made the fetus visible - but at the cost of making the woman in whose body it is cradled invisible. We are left with "man in space" imagery of the free floating fetus, with the woman turned into empty space. This "scientific" picture of the fetus reifies its isolation by erasing its connections, its embodiment within another body.

The root of this, I believe, is patriarchal ideology. I mean that in its very specific, technical sense: not the rule of men but the rule of fathers. In a motherbased understanding of the world, from the perspective of birth, people are what mothers grow, are made of the nurturance, sustenance and care that brings forth a child. In a patriarchal system, a person is what grows out of a man's seed. In a patriarchal System, when we speak of "blood ties," we

speaking of seeds, genetics - the only completely bloodless part of procreation. Our contemporary system is no longer a pure patriarchy, but is modified to recognize the seeds of women as well. Women are understood to be 'related' to their children in the same - and only in the same - way that men are related: through their seeds. Children are "half his, half hers," and might as well have grown in the backyard.

Genetics is the most obvious and direct scientific descendent of patriarchal thinking: an attempt to understand the meanings of things, perhaps the meaning of life, by understanding genes, the bits of RNA, DNA - the updated version of seeds. The Human Genome Project is an attempt to map the human genome, the distribution of genes on chromosomes, to find where each gene lies, and ultimately, what each does. Its proponents are given to waxing eloquent, calling it the holy grail, expecting to find the meaning of life within its C,G,A, and Ts. Its critics frequently describe it as the ultimate reductionist project. And reductionist it surely is. But to define it as the ultimate reductionist project is in a way to accept its underlying premise that we are reducible to our genes. Or, as Alan Spector has put it, the soul has moved into the gene. Genetics attempts to explain people, our physical condition and our social presence, by going back to the beginning, the moment of zygotic zero, when sperm joins egg and the seed is established. Spector is not wrong when he speaks of the soul: In a patriarchy, this is the secular moment of ensoulment.

In a patriarchal ideology, the seed contains all it could be. It is pure potential. Everything else becomes background. Look at a green field. A mother-based world view sees the rich green earth springing forth with life. A patriarchal world view sees seeds put in dirt, in soil. Think about those words we use for the very Earth: dirt, soil. That which is precious and life-giving has moved into the seed; the Earth itself is but dirt, only a place. And so it is that the fetus, the embryo, the zygote, the code becomes essentialized, while the woman, the connections, the social become invisible.

The Human Genome Project is in a sense much like the man-on-the-moon project of 25 years ago. It pulls together a lot of the scientific community, gives it a finite goal, and inspires much talk about human control. But as I think about the human genome project, the words of a Leonard Cohen song keep running through my mind: "No, they'll never, they'll never reach the moon now. At least not the one they're after."

I know this is a minority viewpoint, but I would argue that extraordinarily little has come out of human genetics so far. The basic thing we have is the tea-leaf reading aspect: it is possible to read the chromosomes like tea leaves and make some predictions. In some cases the predictions are quite clear. If the geneticists observe an extra 21st chromosome, for example, the person will have Down's Syndrome. But what exactly that means for the person is not at all clear. If observed in pregnancy, it might mean that the fetus is not strong or well or functional enough to survive the pregnancy and will miscarry, possibly before the results are returned. Or it may be born early and die. Or it could grow into a person with some degree of mental retardation. That could be quite severe or it could be a relatively minor disability. It might turn into a person whose life will be spent locked up in some nightmarish institution; or it might become a person living in a pleasant house down the street. The exactness of diagnosis does not translate into any exactness of prognosis, and no individual prognosis can tell us what social life will offer.

Nor is it clear that a rich and full understanding of genetics will lead to treatment. Consider the case of sickle cell anaemia, where they have in fact a pretty good idea of the cause: the precise molecular structure of the gene is known and for several decades the specific molecular change in sickle cell haemoglobin that is responsible for the condition has been

known. And the treatment? Pain relief and antibiotics. The same treatment you would give if you hadn't a clue what caused it.

But the Human Genome Project doesn't actually need to produce much in the way of cures or even explanation to have its impact. As we say in the watchword of our faith: Situations defined as real are real in their consequences. If we come to believe that the human condition our bodies and souls, our health and our hopes, are genetically determined, that has consequences.

It is so easy to be intimidated by the technicalities, the genetics of genetics, that we might forget what we are doing here... Start bandying about terms like alleles, double helixes and the like, and most of us rather glaze over. But all that this is about is predictions and the predictions are of questionable value. And predictions - perhaps especially predictions of questionable value - are something that medical sociologists have quite a bit of experience with. And so the question I am asking in this paper, as a medical sociologist, is how are genetic predictions used? What are the meanings and consequences of the predictions stemming from genetic testing?

The most widespread use of genetic predictions at this point is in prenatal diagnosis: and so back to the midwives. I will explore what the consequences of genetic predictions in pregnancy have been for clues as to what awaits us with the growing use of genetic testing.

And specifically, the midwives I have chosen to go to, to ask these questions, are the midwives of the Netherlands. The Netherlands remains unique among Western countries in having a fully developed, independent profession of practising midwives, not subservient to the medical profession. That means that they are able to bring an alternative understanding, a birth-centred understanding, to their practice and to their use of the available prenatal genetic and related screening. The Dutch word for midwife is *vroedvrouwen*, or "wise women." In genetics to date we have had much information, but a decided lack of wisdom: I have turned to these Dutch midwives to see if they have some wisdom to bring to bear on these thorny questions. How are they using prenatal diagnosis, how do they see women using this information, and what can that tell us about how people can and will - perhaps should - use the new genetics.

The research I am drawing upon here was conducted as part of a Fulbright Fellowship at the University of Groningen in the Netherlands in 1994. Data presented in this paper came from a series of focus groups conducted with practicing Dutch midwives from all regions of the country. The groups discussed a variety of prenatal diagnostic technologies, not all of which were strictly "genetic" tests, but included ultrasound screening (called "echoscopie" or "echos") as well as maternal serum screening (the "triple test"), chromosome testing and DNA testing. With all of this mixed bag of technologies, the focus is on prediction, which to me is the essence of what genetics means today: do I, does he or she, have "the gene for.."

What is predictable, or believed to be predictable, varies enormously, and there is much talk about a slippery slope: In prenatal diagnosis, the slope is usually graphed as moving from diagnosis and abortion for conditions incompatible with life, passing through the firm but contested territory of Down's Syndrome and neural tube defects, floundering on the rocky terrain of socially undesirable conditions like deafness on down to obesity, bounding along the questionable areas of "gay genes" and "alcoholism genes", and finally crashing into the great moral - abyss of sex selection.

In this paper, drawn from the larger project, I am only going to discuss three sets of circumstances: prenatal diagnosis of conditions which are invariably fatal, in which the baby will die no matter what; the ways that prenatal testing changes the timing of learning of a

disability which would have become apparent at some later point; and the issue of 'reassurances', the false and implied guarantee offered by prenatal testing. In no way should this be read as a complete discussion of prenatal testing. Nor are my criticisms to be read as a complete condemnation of all prenatal testing under all circumstances. Rather, what I am saying is that wise women working with predictive testing have found enormous problems. We are in the process of dramatically expanding predictive testing with the rapid progress of genetic testing. What can we learn from the experience of the vroedvrouwen?

WHEN THE BABY'S DEATH IS INEVITABLE

Ethicists who evaluate prenatal diagnosis are often most comfortable with those situations in which the fetus is diagnosed with an inevitably fatal condition: it might not survive the pregnancy, or even if brought to term and born alive, would die shortly thereafter. In such instances, prenatal diagnosis is generally understood to present no-ethical dilemmas. An abortion simply brings the inevitable to a more rapid conclusion.

Such an approach, like the medical model of pregnancy itself, is both product oriented and fetocentric. The medical model of pregnancy is the model or understanding that is taken-for-granted in most of the western world. The purpose of pregnancy is to make a (healthy) baby: the point of all prenatal and birth management is to achieve that goal. The focus in obstetrical care is on fetal outcome, with the woman variously known as the carrier, host, environment or barrier.

Midwifery, in contrast, is focused on women. That inevitably includes in the management of pregnancy and birth trying to help the woman have the healthiest possible baby. But it also means trying to give her a "good birth", a pregnancy and birth that make her feel good about herself as a mother, as a woman. It is not just the making of babies, but the making of mothers that midwives see as the miracle of birth. There is a general preference for prenatal rather than postpartum visits: Helping the woman is what midwifery is about. And that might very well mean, in a situation where the death of a baby is absolutely inevitable, helping a woman and her family come to terms with that in the best possible way.

In the medical model, the job is to get a healthy baby delivered. If you cannot get that done, then why bother continuing? And that is, in a nutshell, much of the rationale for prenatal diagnosis, and is certainly the logic used for testing for conditions which are incompatible with life. If the baby is going to die anyway, there is no point in continuing the pregnancy. It is a waste of time. And if the woman could have known that and did not, then she has in some sense been duped, made a fool of, wasted her time.

These midwives, in contrast, asked a question that simply makes no sense in the medical understanding of pregnancy. If the baby is going to die anyway, midwives asked, "Why spoil the pregnancy?" The concept of spoiling the pregnancy does not sit well with medically atuned people, largely because the pregnancy, in and of itself, is not valued. Not so for the midwives.

Two midwives in two different groups put it very simply. Considering the possibility of a bad outcome, one said, "Well, do they have to know it? Let them first have an untroubled pregnancy." And another, in a discussion of the possibility of a bad outcome, leaned over and told me quite clearly, "But some of us find a good pregnancy very important, whatever the outcome."

I see two ways of understanding their valuing of a good pregnancy under these circumstances of an inevitable bad outcome. One begs the question: what is the point of life? If life is about accomplishing things, then pregnancies resulting in dead babies are pointless. If life is about living, if it is just this and we only have a finite time to live, then days spent in

joyous anticipation are good days, and days spent in grief are bad days, and prenatal diagnosis of condition inevitably cause death simply moves days from the good to the bad side of the ledger for the woman.

The other way of understanding this - and they are not mutually exclusive – is to postulate that pregnancy has itself a value and a meaning in a woman's life, and that a good pregnancy and a good birth are good things to have.

Consider the following:

In our practice was a child with a disorder that was not compatible with life. It didn't have a midrife (diaphragm). Intestines up, heart on the wrong place, etc. This woman had a good pregnancy, a difficult delivery, but she looks back on it very positively. The child lived a couple of hours. Of course they are sad about the child, but also had very positive feelings toward the child. And I saw a couple of pregnant women talking about it, and they said, "You could have seen it on an echo," which is true. "They should have done an echo, then they would have known." And that is how other pregnant people talk about it, like it's nice to know in advance that something is wrong. Theoretically. But they did not know this woman. This woman is very satisfied that she did not know anything in advance because an echo wouldn't have changed it. Yes, she would probably have had a hospital birth and three thousand echos and pressure, and now it is at least a nice pregnancy and positive experience of her delivery. The outcome would have been the same in both cases.

The outcome to which she refers is the loss of a child, a loss that is inevitable, whether by abortion in the first half of the pregnancy or the death of a born child. This is not at all to claim that all abortions are the loss of a child, but for a woman planning on having a child, a diagnosis of a fatal condition has to mean the loss of that planned-on child. She was pregnant, planning on a baby. There will be no live baby, no living child. The outcome, however achieved, is the same.

In another group a midwife described the unanticipated, untested birth of a baby with anencephaly, an absence-of brain development and inevitable death:

"That night she goes into labor and she gave birth to an anencephaal. She says, "Am I glad that I didn't know!" Because now at least she had a jolly pregnancy. It's really a shame, that baby dies anyway. That's all very sad, but if you know that, that really is quite a burden. She doesn't mind that she didn't know.

A jolly pregnancy: Where is the space for that in the medical model?

One focus group, of midwives from a village in a more traditional and religious area was unique in its opposition to abortion: no other group of midwives could have been characterized as "anti abortion". But even there, with the opposition to abortion, the discussion was both nuanced and continually focused on the needs of the mother. This exchange took place in a discussion of a baby with severe heart disease:

1st midwife: The children's doctor looked at the baby, everything okay. At night, the baby's temperature fell down. It had no chance to live outside the uterus. If I had made an ultrasound the disablement was shown. What will be the profit for this woman? She was pregnant very happy, had a very good delivery, was very happy. However the baby died 24 hours later. But it died in her arms. What if we saw it on the echo?

2nd midwife: No profit, only much worse I think. This was human.

3rd midwife: Once I made an ultrasound, the baby was an encephal, the child had no head. During the pregnancy the woman said goodbye to the baby. That was very important to that woman, so what is profit or loss?

In the medical model, that is readily answered: profit is time saved, loss time wasted. An abortion is an efficient solution. But between the lateness of the diagnosis, and the fact that these are wanted pregnancies, these abortions are not comparable to ordinary, early abortions to get "unpregnant", where the pregnancy was itself a mistake. These abortions, for the woman, are the death of a baby, without the saving grace of a good birth and a good death.

Another group's discussion of diagnosis of inevitable fetal demise concluded:

1st midwife: But isn't it like that most congenital defects aren't compatible with life - so in fact, yes, it solves the case on its own. It might take a little longer, till after the birth, but the woman has had an unconcerned pregnancy.

2nd midwife: Yes, it looks a bit like putting your head in the sand, but on the other side, that isn't it. It's letting nature take its course.

One of the ways to make sense of what the midwives are saying about "jolly" and "nice" pregnancies which result in the birth of dead or dying babies is to acknowledge the distinction between product and process, The medical model is product-oriented; the midwives are process-oriented.

Let me clarify the distinction with a mundane example. Suppose you have a video camera and are filming your kids. They are mugging for the camera, singing a song, playing, laughing and having fun together, when you notice that you have run out of tape, If what you are trying to do is make a tape, then there is no point in continuing - you should tell the kids, stop it, and maybe try again another day when you have fresh tape. On the other hand, maybe you should just continue to do what you were doing, let the kids finish up, let the fun go on, and forget about getting it down on tape.

Partly this is a difference between product and process, but it is also a way of thinking about what the product is: when filming the family, you are also constructing the family, making those very ties between your children that you seek to capture on film.

And now turn to pregnancy: pregnancy is about making a baby, but it is also about making family, making relationships, making the woman a mother. Even if the pregnancy is not successful in producing a baby, it may very well be successful in its other products. Death and grief and sadness also make a family. By nurturing the woman, her relationship with her partner and her family and friends, her feelings about herself and her lost child, midwives can construct success, satisfaction, family even out of death.

For both the medical model and the midwifery model, the Situation of a fetus whose condition is incompatible with life is the clearest. Within the medical model there is no point in continuing, no earthly reason to finish the pregnancy, and every good reason to find out quickly and be done with it. In the midwifery model, since nothing is going to make the baby any better, one has no reason to learn ahead of time and spoil the pregnancy, burden the woman with untimely grief and a ghastly birth-unto-death.

And what can this tell us about the direction of genetic testing beyond prenatal diagnosis? Our destiny may not actually be in our genes, but most assuredly, that is what is being heard: genes "program in" eventualities, serve as harbingers of doom.

How well do people live with predictions of doom? Can we 'spoil a life' or part of one, as we can spoil a pregnancy, taking the joy and meaning out of the present by knowing too well (or

thinking we know too well) where the future lies? I think of people I know who have received very late diagnosis of fatal diseases, whose dying was essentially telescoped into weeks rather than the potential of years that an earlier diagnosis might have meant. Not that more time would have been given to living: more time would have been moved from one to the other side of the ledger. At least for the foreseeable future, genetic diagnosis, the predictive abilities, are far going to outstrip the treatment potentials - just as is true now in prenatal testing.

THE FULLNESS OF TIME

It is not only death, doom and destruction that can be predicted prenatally. More common and more troubling in many ways are the places a bit further down the slope.

Some disabilities - neural tube defects, club foot, cleft lip and palette - are immediately apparent at birth. And some unfold over time. Some of the conditions for which prenatal testing is now available will not show up until middle age. Prenatal diagnosis never tells anything one wouldn't have found out later on anyway. It changes the timing. In having prenatal testing a woman seeks immediately the information she would have had eventually. The reason to seek that information early is that abortion is possible early on. In choosing not to have prenatal diagnosis, a woman may be seen as burying her head in the sand. Several midwives told me about one particular woman obstetrician in the Netherlands who tells her patients who hesitate about having testing that that is what they are doing: burying their heads in the sand. It is the picture of foolishness, turning away from knowledge while exposing oneself to pain. In this, the 'information age,' all information is to be valued for its own sake. And it is precisely that which I am questioning.

When I shared a very preliminary version of this paper with American midwives and childbirth educators, one of them used a phrase that resonated for me: the fullness of time. Let it come, let her learn what she needs to know, but all in the fullness of time. Dutch midwives said similar things, though in less eloquent English: "It's letting nature take its course." Or, in another group:

First midwife: There's time enough to worry about it when the time is right.

Second midwife: When the time is right, yes, well, I do agree with you.

Sounding very much like "burying her head in the sand," one midwife spoke about late diagnosis, information coming past the period when an abortion is possible:

With the echos at 25 weeks and they see something, the pregnancy is spoiled because she has to live with something till birth is coming, because you cannot do anything, or they see the baby has something not with life verenigbaar, compatible with life, what should you do? So I think it is better not to know, just give births and then you will see.

And a second midwife in that group elaborated, explaining that:

The pregnancy is very abstract, you don't make a decision about the child, and when you see the child it is not so abstract any more and you make a decision based on your emotions.

A decision made during a pregnancy, they are saying, cannot be a fully informed decision because it remains an abstraction and the emotions are not there yet. It is an interesting twist on the more usual (male? medical? Western?) notion that emotions muddle and get in the way of informed decisions, that emotions are themselves a pull towards irrationality.

What neither the midwives nor I am saying is that information should be paternalistically or materialistically withheld from women. What we are is are these women who are being tested

making truly informed decisions about the information they are requesting? Do they really want this information? Do they understand what the information will mean to them? And do they understand what it will mean to get the information without the context of the child?

Downs Syndrome presents an interesting example of this problem. It can be absolutely, definitively diagnosed relatively early in pregnancy, as early as 10 to 12 weeks with early amniocentesis or chorionic villus sampling, closer to 18 weeks when diagnosed as part of a mass screening program beginning with maternal serum screening and moving on to definitive diagnosis. At birth, Downs Syndrome is readily identifiable with chromosomal testing, but not always instantly recognizable, especially for the parents. Most of the discussion of Downs Syndrome in midwifery care revolved around disclosure issues: when and how do you tell. An instant appraisal might be actively discouraged. The slowness is valued, the unfolding of knowledge with time. That time, those minutes, hours or days before a diagnosis is given to the parents, serve a purpose. One midwife, telling of a period of several days of confusion before the mother learned the diagnosis of Downs Syndrome said:

I talked later to this woman and she told exactly these days it was for me to adore my baby. If they told it the first day because they thought immediately about it, I cannot adore her. But she is already in my heart, I adore her, I hear she is not okay, but it does not matter anymore, she is already my daughter.

In the language of contemporary medicine and psychology, this is called "bonding," a period in which attachment between mother and baby, and baby and family, is solidified. Pregnancy itself, and the birth process, the midwives claim, serve this purpose. Speaking generally of women bearing babies with problems, one midwife said:

Some women say that when they discover during the delivery that something is wrong, they say "Fortunately I had nine months to bond to the child and it's my child. It's shocking, but I've had nine months a very nice pregnancy which no one will take away from me." And if they would have discovered while they were still pregnant that the child was not healthy... Indeed you never know: how unhealthy is not healthy? What can you expect? And then you have a lot of doubts and you're not enjoying your pregnancy any more.

Midwives talk about the strength that women and families show with the birth of a child with disabilities. The midwives talk about the strength as being there in the woman: I see midwives nurturing women to tap their strengths, playing more of a role in how mothers handle this than perhaps midwives give themselves credit for. But can the woman who can be strong and accepting and loving at birth, who can claim her daughter as her daughter whom she adores unconditionally, that "maybe she's not okay but it doesn't matter anymore," can that woman have those feelings without benefit of the fullness of time? Without the pregnancy, without the child, without the emotions of birth, it is not the same. Prenatal testing, if offered early enough, attempts to bypass all of that, and permit abortions before the child becomes a child. How does one counsel a woman about ending a pregnancy with a fetus that the midwife knows the woman would grow to love? This is the problem, expressed clearly by two midwives in a group's discussion of counselling for prenatal screening. One midwife says she asks women:

First midwife: Which deviations do you think you can handle and which not? I think when push comes to shove you're stronger than you think you are. That's what I see: people who have a child with some kind of deviation are always very strong.

Second midwife, interjecting: Yes, but then they are facing a fact. I don't know how these people would react when they knew it in the 12th week of pregnancy.

Much the same can be said, I believe, for the way people deal with, rise to, their own illnesses, disabilities, trials and tribulations: people do show much inner strength. And yet, that too comes with the fullness of time.

It is in the nature of this growing world of genetic prediction that we offer information 'out of time', abruptly and without context of lived experience.

One of the troubling directions we are now going in is internalizing a new notion of "seeming" vs. "real" health, with "seeming" health being one's feeling and all the standard measures of healthiness. You can feel fine, have good muscle tone, clear thinking, a steady heartbeat, good appetite, rosy cheeks. But that no longer means you are really healthy. Real health comes from a variety of laboratory and new diagnostic techniques. Screening programs paved the way: cancer, heart-disease, diabetes, are all sold as "silent killers." People who think they are healthy may be harbouring these silent killers, death and destruction lurking within. At what point does one "have" or "get", say, cancer? Early (pre-symptomatic) detection gave us the idea that illness lurks, really there before it makes its presence felt. Genetic testing for predispositions seems to build on this, moving the diagnosis back yet again, to a point preceding its physical embodiment, and into the realm of codes, of predestiny, of tragic flaws within.

When I first began working in the area of prenatal diagnosis, I was struck by the oddness of the language problems that arose: how can one speak of a 'disabled fetus'? A 'retarded' fetus? What exactly is it that a disabled fetus is unable to do that a normal fetus can? A retarded fetus? And try to think of what it means to predict alcoholism genes: can there be an 'alcoholic fetus'? Is a 'gay fetus'? a *reductio ad absurdum*? With genetic testing for the breast cancer gene, we now can have three year old girls who essentially have breast cancer before they have breasts.

Lived illness, disability, disease, infirmity most often comes in a context, in the course of a life, unfolding itself over time, with good days and bad days spiralling downward. You adjust. What comes to be thought of as a good day was once a very bad day indeed.

When a diagnosis clarifies and names an existing problem, labels it for us, it may be useful. It may also, as we well know from the field of labelling studies, be dangerous, harmful, disruptive, stigmatizing, punitive. What we need to think about as our labelling abilities expand is what are the consequences of labels without the conditions they signify?

One of the comforting stories we tell ourselves is that all of this labelling, diagnosis, prediction, will lead to prevention. We like to believe that if we could identify those people who are prone to, say, middle-age onset diabetes, for example, we could get them to eat properly and exercise, and avoid the disease. And yet we know perfectly well that people with diagnosed diabetes, people who are actively and physically suffering the consequences of their disease, cannot always, or even often, manage the programs designed for them. People with lung cancer smoke: Does anyone seriously think that identifying people with the genetic predisposition for lung cancer is going to stop the 12 year old with the gene from smoking?

And what about the 12 year old without the gene for lung cancer? Not having the "gene" in question does not mean one is home free, not at risk of environmental consequences. Women without the gene for breast cancer have learned that their risks now drop down to the regular risks of breast cancer.

While a diagnosis of having a gene that predisposes towards a particular condition may be experienced as an abrupt diagnosis of doom, a diagnosis of not having that gene implies a false guarantee.

NO GUARANTEES

Midwives know that birth, like life itself, comes with no guarantees. A belief in the health and normalcy of pregnancy and birth is not to be confused with a fantastical expectation of all jolly pregnancies, happy healthy babies, well-adjusted mothers and eternal happiness. While critics of midwifery may fail to understand this, and confuse 'the midwives conviction about the 'naturalness' and healthy nature of pregnancy and birth with a naive, Pollyannaish expectation of happy endings, the midwives themselves hurl this very accusation at the testing process.

The testing, they find, implies for many women a kind of guarantee. Women say they want the testing for reassurance, for security. One group discussed uses of ultrasound:

1st midwife: They want to know if everything will be OK.

2nd midwife: They want security.

1st midwife: Security, yes. They want a kind of security, but then I say they can see a lot, but there are so many diseases they can't see. So it will give you not a real security. You can explain it, but not to all women.

3rd midwife: It gives security. "I'm so glad I have seen the baby and the doctor said everything was okay. And you could see the kidneys and the heart. It was quite nice." So I'm scared about that security.

And then the examples follow, in group after group, of women reassured and then surprised. From another group, in a discussion of a woman who had a child with disabilities in her first pregnancy and then considerable testing in her second:

1st midwife: Then she was pregnant again and she really went 20 times for an ultrasound as well in - as in here. This time it's a fantastic child and she wanted to give birth at home. So, there comes some eight-pounder, and it has ONE HAND and nobody noticed that before. Then you stay there and you know, met je mond vol tanden (with your mouth full of teeth, 'speechless.') I felt it soft below my feet. I never felt worse.

2nd midwife: And she got the impression, everybody looked at it so many times, there will be no problem that's what you expect, but then...

3rd midwife: Yes, it's a kind of false protection.

1st midwife: A short time ago we had a woman with very strange (fetal) heart tones, so they made an ultrasound. They told the little heart was all right, there were no abnormalities. The child is born, six weeks after birth it appears the child has a severe abnormality of the heart, which has not been seen on ultrasound. In some ways you can see nice things with It but it also misses some things. The problem is people have so much confidence in it. For them the ultrasound is "when I had an ultrasound it will be all right."

I think the midwives tell each other these stories not just to carp about inaccurate testing, but because it raises a fundamental issue in the meaning of testing, an issue we would do well to think about as genetic testing increases. Testing is about control, as if information led to control. Several midwives mentioned women wanting early ultrasounds to reassure them about miscarriages. But all that early ultrasound will tell them is what they already knew: that they are at that moment carrying a fetus. That you can see it on Monday doesn't mean it will be there on Tuesday.

That is why midwives aren't just irritated by these false negatives, these false reassurances, but as one said, scared by that security. Some see this as a product of changing times. "But it suits in these times we live in, we want to arrange everything, we want to control". Some recognize it as very specifically an American way being exported to the Netherlands. As midwives find their clients asking for more testing, some say it is the city women more than the village women, or the ones who 'read everything'. Some say it is the media, the magazines, the stories. Some see the push as coming from some of the research centres within the Netherlands. But all are aware of these winds of change as a new search for security. And it scares them.

It scares them because this isn't just about pregnancy. This is about motherhood and about life itself. In counselling people, one midwife says:

It has something to do with someone's personality, the way he copes with deformation in life, isn't it? Like he can accept, or not, a child with a handicap. I always explain it is not true that you don't have to worry anymore when the pregnancy is passed. You are eager to have a healthy child, but after a chorionic villus sampling, amnio, an ultrasound and birth, your worries are not over yet. When the child is there you still have your concerns. Can he walk along the street on his own, and near the water, I hope he gets no accident, and I hope he doesn't get some wrong friends. It is a process, all life long isn't it? Somehow or somewhere you have to let it go, you cannot control everything, and maybe you have to start to let it go at the beginning. You should dare to leave some questions without an answer.

The demands of the Information age drive us towards getting all of the answers. Perhaps wisdom lies in not always doing so, in making wise judgements about which information we want, and which information we do not, about when we want information and when we want to wait.

We are not to live forever. There are no happily ever afters, Life is a very scary place and you're not getting out of here alive.

This human genome project hasn't only been about a search to know - it's been about control, as if information led to knowledge and knowledge led to control. This is clearly not about making people better off - we as sociologists ought to know that. People don't get better off one at a time: we are and we remain social beings. Postal codes are still our best predictor of infant mortality rates.

As medical sociologists we should know this: not only in social life, but even in that area of life known as medicine, as illness, as the body, reductionism won't work, not to explain, not to help. There have been a few exceptions, certainly, just enough to keep it funded. The odd gene that prevents a particular kind of protein from being metabolized and creates havoc is found: and from that, all health, all illness, all bodily states are believed to be found in the genes.

But essentially, in our essence, in our fibre and being, we are not isolated pre-programmed bits of DNA. We are part of our social world, deeply entwined with one another. That is the wisdom of the vroedvrouwen, of the midwives: an understanding of the connectedness. It is an understanding, a wisdom that sociology - when it is working right - shares, a sense of our connectedness, our context, our social essence.

And what we need, as we muddle through this life, is probably less information and a lot more wisdom.

Health, Medicine And Risk: The Need For A Sociological Approach

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INTRODUCTION

In May 1994 Britain was gripped by a panic about a deadly, quick spreading gangrene known as necrotising fasciitis. The media, particularly the tabloid press, were full of horror stories about 'the killer bug', linked with the streptococcus group A bacterium, with new victims being identified with each day that passed. Of the cases that had come to light by the end of the month 11 had died. While one expert, a professor of bacteriology, claimed that he had evidence the bacterium was becoming more virulent, thereby heightening public concern, another, the Director of the Public Health Laboratory Service, which monitors diseases and provides advice about the control of infection, tried to assuage this concern by stating that reported cases were within expected annual figures. The Service's response was also echoed by the Government which refused to make the infection a notifiable illness, requiring doctors to report it, as it felt that no new information would be gained.

Eventually the tabloid press lost interest in the story and broadsheet leader writers were left to reflect on the significance of this latest health scare and why the nation's psyche had been gripped by it. One response was that it highlighted a 'mixed-up perception of risk' in modern society, with people in reality experiencing far greater risk from driving a speed on a motorway, smoking and lack of exercise than from diseases such as necrotising fasciitis (Guardian 1994). Another was that public concern reflected a realisation that science and technology were as baffled and helpless in the face of this disease as ordinary people (Observer 1994).

This episode encapsulates nicely the way in which 'risk' is now a major issue for lay people and experts, journalists and government. The risk of 'rogue' micro organisms is, of course, only one of a number of threats to health. The risks to personal health from poverty and an unhealthy lifestyle are equally important, and are paralleled by public risks from industrial, agricultural and technological processes.

The Risk Industry

The term risk is not new of course. It is derived from the French word *risqué* and first appeared in its anglicised form in England in the early nineteenth century (Moore 1983). Originally it was employed in a neutral fashion as a wager made by individuals after taking account of the probability of losses and gains (Dake 1992), it has come to refer in more recent times only to negative outcomes (Douglas 1990); to the likelihood of some adverse effect of a hazard (Short 1984).

Over the last three decades a veritable industry has developed concerned with risk and, in particular, risk assessment, drawing primarily on disciplines such as engineering, toxicology, biostatistics and actuarial science, and institutionalised in the Society for Risk Analysis and the journal *Risk Analysis* (Golding 1992, Hayes 1992). Perceiving risk assessment to be essentially a technical matter to be resolved by developing more accurate scientific information, physical and life scientists and government agencies have sought to develop

'rational' means to make decisions about health risks. Emphasis has thus been placed on developing quantitative measures which can facilitate comparing the risks of different choices, calculating their costs and benefits (often in monetary terms) and communicating these to the public and to government (Nelkin 1989). The aim of such exercises is to find out what the risks really are on the assumption that all risks are discoverable and measurable and can be controlled with the requisite skill and expertise (Thompson 1989). Such optimism is in marked contrast to earlier times when attitudes towards risk were usually fatalistic, and danger and uncertainty were managed primarily through prayer, sacrifices and other rituals (Herzlich and Pierret 1987).

The current 'rational' approach to risk has become particularly popular with industrial managers and developers who have recognised the need to employ risk analysts to assess (and legitimize) the environmental risks of new technologies, in the face of legislation and mounting public concern about industrial hazards following a series of disasters. Accidents such as that of Seveso in Italy, Three Mile Island in the United States and Chernobyl in the Ukraine have illustrated the limitations of recent technological developments and the enormous health costs when things go wrong (Brown 1989). Faced with such public concern risk communication strategies have been developed, aimed at bridging the gap between public and expert perceptions of acceptable risks (Golding 1992). Despite such developments lay opposition to technologies such as waste incinerators and nuclear waste repositories grow ever more vocal, especially in the USA (Cvetkovitch and Earle 1992) which is now faced by what has been called 'technological gridlock' (Irwin 1995).

Assessing risk has also become a major issue in the health field. In curative medicine much effort is now expended calculating the risk of various medical procedures and technologies and techniques have been developed to reduce the risk of iatrogenic diseases. Risk management, monitoring devices and systematic surveillance of perioperative complications have all been introduced in healthcare systems in industrialised countries in an attempt to reduce risks and control costs (Skolbekken 1995). This has been particularly the case in insurance based systems where the increase in premiums is of major concern (Brown 1979).

Assessing risk has also become a key element of public health as the account of 'the killer bug' panic described above illustrates. Epidemiologists calculate the 'relative risk' or numerical odds of a population developing an illness when exposed to a 'risk factor', compared with a similar population which has not suffered such exposure (Frankenberg 1994). It is on the basis of such risk assessments that governments have conducted health education campaigns to warn the public about the dangers of certain activities, presuming that 'risky behaviour' will be reduced as a result of the information transmitted.

According to Lupton (1993) public health discourse about risk can be divided into two kinds. The first concentrates on the environmental level and considers the risks to particular populations from nuclear waste, pollution and other hazards. The emphasis here is thus on the by-products of economic and social activity and the need for health promotion policies to maintain purity of the natural environment (Armstrong 1993). While dangers are everywhere, they are seen as external to and outside the control of individuals. An environmentally friendly, ecological response based on legislative action is therefore advocated as the main way of reducing risk and achieving a healthy environment (Beattie 1991).

The second form of discourse, by comparison, constructs risk as the consequence of the 'lifestyle' choices made by individuals, and emphasises the need for self control. To this end health persuasion strategies are designed and transmitted through convenient media to warn people about health risks (Beattie 1991), on the assumption that knowledge about the dangers of certain lifestyle activities will result in their avoidance (Lupton 1994).

The second public health approach is clearly illustrated in the AIDS field where gay men have been identified as having a higher risk of getting AIDS compared with heterosexual men because of gay 'life style' practices such as anal intercourse and multiple sexual partners. In this case risk has been calculated on the questionable assumption that all gay men ascribe to a single set of cultural practices and values (Glick Schiller et al 1994). These assumptions have, in turn, underpinned government health education materials about AIDS, encouraging the 'general population' to perceive HIV infection as a problem which concerns gay men rather than heterosexual men and women (Glick Schiller et al 1994).

Social theories of risk

Until relatively recently sociologists have paid little attention to risk analysis (Kronenfeld and Glick 1991). Those that have, like anthropologists, have taken as their starting point that risks are socially constructed or framed and collectively perceived. Where they have differed has been in their concern with material constraints and social interests as well as cultural factors in shaping risk perceptions and their management. Much of this work has been theoretical in orientation but there has recently been an increasing interest in undertaking empirical research in this area, especially amongst medical sociologists.

Social analyses of risk as they relate to health can be divided into those micro level studies which concentrate primarily on what C. Wright Mills (1959) famously called 'personal troubles of milieu' (concerning the individual's self and those limited areas of social life of which she or he is directly or personally aware) and more macro level work concerned with 'public issues of social structure'. The latter refers to things which transcend the individual's local environment and the range of his or her inner life and are seen by the public as threatening some cherished value. I shall briefly consider each of these approaches in turn.

Micro level studies in the health field have been concerned with the meanings of risk and the ways in which these are used to achieve practical results. Those taking this interpretive approach have tended to concentrate on two broad areas: perceptions of risk and risk behaviour and the relationship between lay and expert knowledge of risk. In the former area attention has focused on how people interpret risk rationally and instrumentally within the circumstances and constraints which impinge on their daily lives. For example Becker and Nachtigall (1994) have examined how the quest for pregnancy affects the construction of risk by couples going through infertility treatment. They show how such perceptions are shaped by biography (the women's deep rooted desire to have children) and bodily knowledge, their ongoing experience as patients in the health care system and by cultural values about fertility (conceptive technology mobilises and reinforces faith in 'persistence' as a way of achieving one's goal).

The role of contextual factors in risk perception also feature in Parsons and Atkinson's (1992, 1993) work on lay construction of genetic risk. They show how women live with the risk of Duchenne Muscular Dystrophy and how awareness of being 'at risk' is related to critical junctures in the life course such as the beginning of courtship or being in a stable relationship and wanting to have children. Perceptions of risk were also shown to influence whether the women were risk takers or risk refusers, although other biographical factors such as prior reproductive desire and the structuring of genetic information in personal stocks of knowledge were also found to be important.

The second and related area of interest for micro sociology has been the relationship between lay and expert perceptions of risk. One example of this in the health field is the work of Davison et al. (1991). In their study of lay beliefs about the risk of coronary heart disease (CHD) in South Wales they found evidence that both mirrored and diverged from expert

opinion. While those interviewed agreed with the health promotion experts that they should accept some responsibility for their health and could minimise the risks of CHD by reducing smoking and altering their diet they also drew on other ideas which differed from and to some extent conflicted with official thinking. In particular they referred to the social circumstances surrounding the occurrence of CHD and drew on more fatalistic ideas when either personalistic or social types of explanation seemed inadequate. Thus they demonstrated lay people's willingness to assess rationally official information on the risk of CHD and apply it to their lived experience on an ongoing basis.

A similar concern with comparing lay and professional views has been demonstrated by Roberts et al (1992, 1993) in their study of the risks of childhood accidents in Glasgow, Scotland. They too found some common ground between the two groups – in this case parents on a local housing estate and professionals with some occupational responsibility for the estate - but also considerable differences. For instance while both groups saw parents as responsible for the safety of their children, the parents had considerably more knowledge of local hazards and risks, were much more likely identify specific administrative bodies as responsible for these hazards (rather than talk in terms of generalised social responsibility), and advocated a wide range of structural improvements and a greater sharing of local resources (instead of relying on education) in order to prevent accidents. The Glasgow respondents however differed from those in South Wales in that they were not fatalistic or complacent and stated that they routinely took measures to minimise the risk of accidents.

In addition to this interpretive research on group risk perceptions and behaviour there has been some more macro level work on the role of social institutions and structures in the framing of risk. As noted earlier in the example of necrotising fasciitis, the mass media play an important role in public perception of risk. They serve as filters through which both lay people and experts - both policy officials and health professionals - receive news and interpret events (Nelkin 1989). Though the selection and coverage of particular health stories they set the agenda of public discourse and affect the priorities which guide an individual's risk behaviour.

Surprisingly, given the importance of the media in risk communication (Nelkin 1989). There have been relatively few attempts by sociologists to analyse its role in the perception of health risks. With the exception of a few studies concerned with press coverage of occupational health issues (Raymond 1985) and road safety (Stallings 1990), most of this small body of work has been concentrated on the content and reception of AIDS coverage. For example, Nelkin (1991) has discussed what shapes the content of press and popular magazine coverage of AIDS in the US and the way such coverage is received. She shows how the constraints of newswork and the need to rely on external sources to explain complex technical information about which there was some uncertainty, shaped coverage of AIDS. In addition, she suggests these media messages have been influential in making AIDS visible to lay people and turning it into a public issue which required a regulatory response, if only to protect the agencies public image. In Britain similar work on the production, content and reception of AIDS messages has been undertaken by the Glasgow University Media Group (Miller and Williams 1993, Beharrell 1993, Kitzinger 1993).

One of the external sources of information journalists turn to for information about particular risks are social movements. These campaigning groups make claims about the risk status of what they perceive to be environmental, technological or medical developments, and in the process help construct such dangers as social problems worthy of public attention (Short 1984).

Again there has been relatively little research on the role of social movements in defining health and medical risks as public issues. One exception is Elston's (1994) study of the anti-vivisectionist movement in the UK. She shows how the contemporary animal rights movement has deployed arguments about the risks and limitations of modern medicine from within academic social science and medicine to provide an 'external' critique of the utility of medicine.

In addition, there have been a limited number of studies of community based protest movements and their attempts to turn local environmental health hazards into a public issue. For example, Williams and Popay (1994) have documented how local residents in Camelford, North Cornwall challenged two government-backed reports by an expert group on the health effects of the poisoning of their water supply. The case was taken to show how 'popular epidemiology' the synthesis of political activism and lay knowledge - was used to challenge scientific criteria for assessing risk and experts' claims to technical knowledge. Other studies with a similar focus include Brown's (1992) ground breaking work on the identification of and response to a leukaemia cluster amongst children by residents in Woburn, Massachusetts and Phillimore and Moffatt's (1994) research on the role of local knowledge in explaining the link between industrial air pollution and the health of people living nearby.

The focus of these studies on the relationship between lay and expert knowledge in turn reflect a more broad based theoretical concern amongst social theorists about the declining trust in expert authority in late modern societies. According to Giddens (1990) we are living in a period in which the judgements of experts are constantly open to scrutiny or 'chronically contested', and are either accepted or rejected by lay people on the basis of pragmatic calculations about the risks involved. In such circumstances even the most cherished beliefs underpinning expert systems are open to revision and regularly altered, and the dominant source of authoritative interpretation is undermined (Giddens 1991).

The depth of ambivalence or alienation which people feel towards experts and risk management institutions in turn relates to a recognition that we now live in a 'risk society' (Beck 1992a 1992b); that is, one that is increasingly vulnerable to major sociotechnical dislocation and growing interdependency. Social and economic processes have created global nuclear, chemical, genetic and ecological hazards for which there is no satisfactory aftercare. These structural features reinforce the need for trust in expert authority at the very time that increasing reflexivity and a growing recognition in the indeterminate status of knowledge about risk work to undermine it. In a 'destabilised' and 'runaway' world the landmarks of a more certain era are displaced by the 'politics of anxiety' (Turner 1991).

Faced with such anxiety the role of the medical sociologist is perhaps to attempt to help further develop an alternative to the existing technical approach to risk assessment by revealing the socially constructed or framed nature of health risks and the various plural rationalities involved (Thompson 1989). The following questions may provide the focus for such work:

- What role do social, cultural and institutional processes play in the perception of health risks?
- How are the processes of defining health risks related to cultural attributes of blame and responsibility?
- To what extent do calculations about the probability of health risks influence decisions and actions of specific social groups?
- How do expert and lay frames of reference with regard to particular risks differ?
- How are public health risks constructed and legitimated by scientists, the mass media, government agencies and social movements?
- What are the constraints and opportunities for social movements to challenge expert assessment of public health risks?
- To what extent is trust in experts' assessment of risk undermined in late modern societies and with what consequences?
- How do expert discourses on health risks throw light on key elements of social order and cultural change?

By addressing these questions which cover the gamut from micro processes to macro issues of social order and social change, medical sociologists may make an important contribution to the debate about the private risks which people face and the ways in which public dangers are managed at the end of the twentieth century. The issues raised are too important to be left to the 'risk industry'.

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Strategies used by healthcare practitioners to manage fatigue-related risk: beyond work hours

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ABSTRACT

Objectives: Fatigue in healthcare practitioners presents a risk to both patient safety and the safety and well-being of doctors and nurses. Management of fatigue-related risk is largely focused on hours of work limits, but these limits are fallible. The aim was to investigate the ways in which healthcare professionals manage fatigue-related risk beyond the hours.

Methods: Qualitative data extracted from semi-structured interviews and focus groups with 189 healthcare practitioners from nursing and medical disciplines were subjected to thematic analysis to identify key themes of causes and consequences of fatigue, as well as strategies deployed within teams and by individuals.

Results: The majority of fatigue risk management beyond hours of work limits occurs as informal processes that have evolved within teams. These processes can be characterised as non-technical skills and include error protection practices and fatigue-proofing strategies.

Conclusions: The informal practices we identified represent a key layer of defence in a fatigue risk management system – that of recognising and responding to fatigue. A process to assess and formalise the error protection practices and fatigue-proofing strategies is required and any formal implementation should be supported by effective and fair incident reporting systems.

Keywords: Risk management, fatigue-related risk, fatigue-proofing strategies, error protection

INTRODUCTION

Healthcare practitioner fatigue presents a risk for both patient safety, and the safety and well-being of health professionals in hospitals and clinics. Fatigue arises as a result of work-related and non-work-related factors including night work, extended hours, inadequate sleep and high workload (Williamson et al., 2011, Gander et al., 2011). Impaired performance associated with elevated fatigue can manifest in various ways, including slowed reaction times, poor decision-making and increased rates of error (Akerstedt, 1991, Folkard and Tucker, 2003, Harrison and Horne, 2000). In healthcare, fatigue is associated with human error and adverse outcomes for patients and healthcare professionals (Wilson et al., 1999, Committee on Quality of Health Care in America, 2000, Committee on Optimizing Medical Trainee (Resident) Hours and Work Schedules to Improve Patient Safety, 2008, Nichols et al., 2008). Risk management systems are designed to reduce the likelihood and consequences of workplace errors and incidents (Reason, 1995, Standards Australia, 2009) including human error associated with fatigue.

Fatigue risk management systems manage the likelihood and consequences of fatigue-related incidents using a system of multiple defences. While variations exist, broadly the defences focus on hours of work and staffing for workload, sufficient sleep, recognising and responding to signs of fatigue or lowered alertness, and learning from errors and incidents (Dawson and McCulloch, 2005, Lerman et al., 2012). It is often the case that fatigue is characterised as being largely about work hours. While there is no doubt that work schedules impact sleep and clinical performance (Lockley et al., 2004, Landrigan et al., 2004), a reduction in total work hours may not always equate to a reduction in risk. For example, indirect effects such as diminished quality of teaching for trainee doctors through reduced exposure to cases, increased workload for senior physicians and disrupted continuity of care have been discussed in other forums (Dawson and Zee, 2005, Dawson and McCulloch, 2005, Gorman et al., 2005) and will not be revisited here. Either way, although hours of work limits are necessary, they are not sufficient to manage risk. Compliance with hours of work limits does not guarantee adequate sleep and low fatigue-related risk. Thus, while management of work hours must remain a focus, fatigue-related risk to patient and healthcare practitioner safety should be managed using multiple layers of defence (Reason, 1990) that involve not only organisational elements but also individual and team-level elements.

Healthcare professionals, both as individuals and as teams, use a range of essential technical skills and competencies, to ensure appropriate management of patients. Importantly however, non-technical skills and competencies are also critical to safety and efficacy and complement procedural or technical elements (Kodate et al., 2012). Non-technical skills are broadly defined as the cognitive and social skills needed to perform a role and include teamwork, communication, monitoring, leadership and decision-making (Kodate et al., 2012, Flin et al., 2008). Within healthcare teams, recognising and responding to fatigue could be categorised as a non-technical skill and represents a potential layer of defence against a fatigue-related incident. However, the use of non-technical skills to specifically manage fatigue-related risk in healthcare has not been investigated. The types of fatigue management strategies used by healthcare professionals (if any) are not well described, and there has been little research focus on the management of fatigue-related risk in healthcare beyond work hours. In order to shed some light on how fatigue-related risk is managed in healthcare, the current study investigated (i) the causes and consequences of fatigue for patient, individual healthcare professional, colleagues and community, and (ii) the strategies used by healthcare practitioners to manage fatigue-related risk. In addition we elicited information about perceived barriers to fatigue management.

METHOD

Design

The design was qualitative and used focus groups and semi-structured interviews to collect data. Focus groups were conducted in semi-structured format with individuals from the same unit, during 90-120 minute sessions (n=164 participants in 11 focus groups). Semi-structured, one-on-one interviews were conducted over 30-60 minutes either in person, or over the phone (n=25 participants). Topics covered in the focus groups and interviews included – causes and consequences of fatigue, strategies used (or have knowledge of) to manage fatigue, barriers to fatigue management in healthcare. The protocol was approved by the Human Research Ethics committee of the University of South Australia.

Participants

Participants volunteered to be involved in the study and were medical and nursing staff who worked in: one of seven Australia states/territories (SA, NSW, QLD, WA, VIC, TAS, ACT); public or private facilities; emergency medicine, surgery, obstetrics and gynaecology, pathology, intensive care, anaesthesia or mental health departments; tertiary teaching hospitals, secondary or peripheral hospitals, or rural/remote medical centres/clinics.

Data analysis

Interviews and focus groups were transcribed and analysed using thematic content analysis (Braun and Clarke, 2006). A coding framework was developed for each of the main questions – Causes of fatigue, consequences of fatigue and strategies to manage fatigue - using an inductive approach. This allowed subthemes to emerge without restriction.

RESULTS

Causes of Fatigue

Causes of fatigue were categorised into personal and organisational themes (Figure 1). Organisational sub-themes of workload and culture emerged and were linked to personal sub-themes of sleep and stress. Sub-sub-themes under the workload and culture sub-themes included work hours scheduling, work role and work practices. For example, participants reported that long and extended shifts reduced the opportunity to sleep and resulted in extended periods of wakefulness.

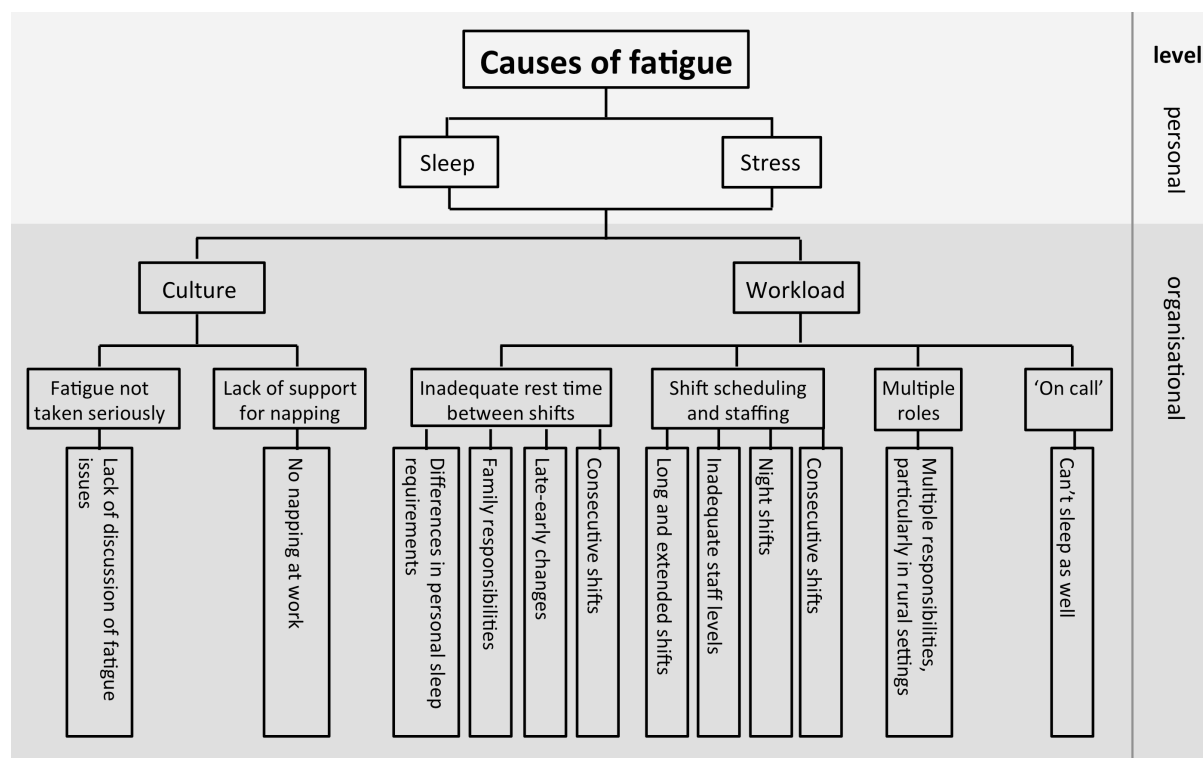


Figure 1 – Causes of fatigue as reported by healthcare professionals, categorised into key themes.

Consequences of Fatigue

The consequences of fatigue were categorised into themes of ‘Who was affected’ and ‘How they were affected’. Figure 2 presents specific consequences, grouped into category of

consequences and further categorised according to the impacted party. Consequences ranged from direct impact on patient safety as a result of error, through indirect effects as a result of poor communication or negative mood, to risks to the individual healthcare professional and other road users on the work commute. At the extreme end of the scale, respondents discussed examples of direct harm and even fatal consequences to patients as a result of fatigue-related error. More common however were errors such as incorrectly administered medication and reduced legibility of hospital documentation (e.g. notes, patient charts). The consequences in the mental fatigue sub-theme included decreased concentration, slowed reaction time, and impaired ability to perform reflex tasks. Respondents also reported increased irritability and mood changes which were associated with changes in communication and interactions with both colleagues and patients.

The personal sub-theme included elements of individual safety and wellbeing, in particular an increase in fatigue related illness, poor nutrition and prescription drug use to aid sleep. Fatigue-related incidents on the road included situations where the safety of participants was compromised, as well as other road users and pedestrians. The majority of crashes were reported to occur in the early morning, as individuals returned home from night shift.

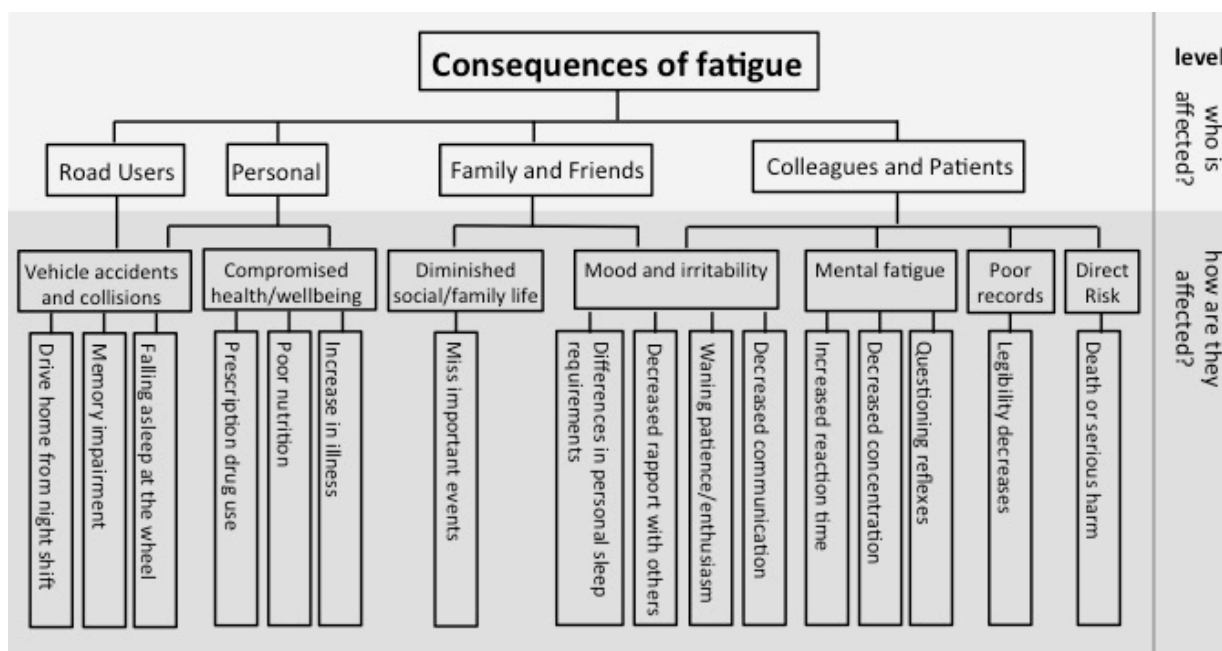


Figure 2 – Consequences of fatigue as reported by healthcare professionals, categorised into key themes.

Strategies used to manage fatigue-related risk

Strategies were categorised based on their current formal or informal use, and potential strategies (participants have heard about their use in other facilities, or believed them to be a viable option). Table 1 provides characteristic responses for each Strategy sub-theme.

Current strategies

Formal strategies discussed by participants were almost exclusively related to work hours or the roster. The only other formal strategy discussed was the supply of taxi vouchers, however where the policy was in place, very few participants reported using the vouchers.

Individual fatigue countermeasures identified in the analysis included the use of caffeine and taking breaks, in addition to keeping busy. Informal strategies used by individuals within

teams were categorised into work practices and error proofing practices. Work practices included prioritising finishing times for those staff with the shortest break between shifts, facilitating napping by batching night-shift tasks, and rotating night-shift naps across a block of consecutive shifts within the team. Error-proofing practices included a conscious increase in communication, double checking oneself or asking colleague to double check, focusing on one task at a time, undertaking an alternative task for a period of time, and deferring decisions either to later or to a colleague.

Potential strategies

Discussions of potential strategies for managing fatigue-related risk in workplaces focused mainly on working hours and staffing, but participants also discussed incident reporting as a strategy (Table 1). Other potential strategies could be categorised as system-wide issues such as increasing both the system-level and consumer-level acceptance of continuity of care as opposed to continuity of carer through education or different approaches to handover, or organisational-level strategies such as rostering more appropriately for workloads.

Barriers to implementation of strategies

Barriers to fatigue management fell into three categories: individual factors, largely in relation to personal responsibility for work and non-work time; organisational factors including staffing, workload, financial, cultural issues; and community-based issues such as expectations for service delivery or availability (Table 1).

TABLE 1 – Representative quotes from focus groups and interviews illustrating strategies and barriers

Strategies for managing fatigue-related risk*Informal strategies*

“When we have a late-early, the person with the early the next morning, they do handover first.”

“an informal process is to write down all the non-urgent things and when the list gets to 12 then call the doctor”.

“Have been in theatre and said I am not doing the next one and went home, called the consultant in”

“I said if we don’t cancel this elective surgery I’m resigning, its unsafe”.

*Potential strategies*Work hours

“perhaps if more of a break or a sleeping day could be included when coming off night shift...”

“Practical strategies written into policy would be useful, like breaks.... Do what the nurses do...”

“Certain people cope better with nights than others. If people don’t sleep at all don’t put them on nights.”

Reporting

“Educate more people, consultants, nursing staff and team leader so that when someone says they are tired then they are supported.”

“A process to tell senior person. If same people frequently reports then can investigate.”

“It would have to be anonymous, might be good for a nation-wide database, would need to be very supportive.”

Work practices

“Better handover like nursing.”

“Friend in the US works in a facility where patients are referred to and admitted to the ‘clinic’, not to individual doctors. The patients belong to the clinic not to individuals. This is easier for physicians than for OG or surgery.”

“We have three regular meetings now that are reflection meetings. ... discussion of cases and reflection of things that have gone wrong. ... balance between accumulation of experience and learning from errors.”

Barriers to fatigue management strategies

“Junior doctors starting out are not given any advice on how to deal with late nights, or night shifts i.e. what to eat, how to program body clock, what to expect with regards to decision making, memory and emotional response” (Junior Medical Officer, Questionnaire)

“The crux of the discussion of balancing fatigue with clinical work is that we work as individuals rather than as a team. You can’t easily substitute one person for another.”

“In big centres they always say take your breaks and put your hand up if you are struggling but you know that if you are struggling and very busy then everyone else probably is and stopping just loads of the rest of the team.”

“Its not a problem til it’s a problem for the people who can fix it.”

“Community expectations are that if someone is going to cut your head open, then you want to talk to them.”

“Don’t think the community is that unreasonable of we put the case to them, what they do want is appropriate handover.”

DISCUSSION

The goal of the current study was to understand the ways in which fatigue-related risk is managed in healthcare facilities, beyond the roster or scheduling of work hours. Using qualitative data analysis, we investigated the causes and consequences of fatigue for healthcare practitioners in both medical and nursing disciplines in a range of facilities, in addition to the strategies used by these professionals. The analysis showed that a large portion of fatigue risk management in healthcare occurs by way of informal processes that have been tailored to the specific workplace or team. Despite the current informal use, there is significant potential for implementation of more formal processes, possibly through or proceduralisation of effective fatigue-proofing strategies and error protection practices. The contribution of informal strategies and practices to fatigue risk management in healthcare will be discussed in conjunction with the critical role of incident reporting in safety management systems.

Risk management and safety management system science provides strong evidence for the effectiveness of multiple layers of defence against the risk of incidents and accidents (Reason, 1990). In relation to fatigue risk management, work hours are a critical component in managing fatigue-related risks to patient safety and healthcare practitioner health and well-being. However, fatigue risk management systems should also include additional layers of defence such as recognising and responding to signs and symptoms of fatigue, and reporting errors and incidents (Dawson and McCulloch, 2005, Lerman et al., 2012, Gander et al., 2011). Recognising and responding to elevated fatigue risk could be characterised as a non-technical skill, and a critical layer of defence in a fatigue risk management system. The current study demonstrates that while that layer does exist in healthcare, it appears to be largely informal in its application.

Beyond work hours, fatigue risk management in healthcare facilities is almost exclusively situated in informal strategies deployed at the individual and team level. These strategies represent non-technical skills and include communication, teamwork, leadership and monitoring functions (Flin et al., 2008, Kodate et al., 2012). Participants in the current study identified both individual and team-based strategies that they used routinely to mitigate the risk of error. Interestingly, the strategies focused either on reducing the likelihood that an error was made (e.g. defer decisions, focus on one task etc.) or on reducing the consequences of an error (e.g. double checking to catch errors). The modifications to work practices and use of specific error protection practices closely align to the suite of non-technical skills taught in crew resource management training in aviation (Helmreich, 2000, Helmreich and Merritt, 2000). Our study did not investigate the methods by which these strategies and routines are transmitted between individuals and teams. It would be interesting to examine the degree to which these safety behaviours are universal and to identify the signals that are used by healthcare practitioners to trigger the implementation of the strategies. On the surface, the use of these error protection and fatigue-proofing strategies appears to be a 'recognising and responding' layer of defence against fatigue-related risk but participants were not so explicit in their explanation of how and why they use the strategies. An obvious but as yet unanswered question is whether the strategies are actually effective in maintaining patient safety.

The current investigation demonstrates a significant lack of reporting of fatigue-related error or incidents by healthcare practitioners. Reporting errors and incidents in order to facilitate continuous improvement of the system is a critical element of FRMS (Lerman et al., 2012, Gander et al., 2011) and safety management systems more generally (Anderson et al., 2013). Our analysis indicates a willingness to report if the information is used appropriately

and fairly. Indeed, the use of incident reports should form the basis of an evidence-based continuous improvement process, provided they are implemented and function appropriately (Thomas et al., 2012). Thus, while organisational culture is considered important in the management of fatigue-related risk, it is currently considered a significant barrier.

The culture of the organisation, including the way in which decisions are made about staffing and workload, was a major subtheme discussed in terms of barriers to fatigue management in healthcare. One of the quotes that characterised the view in relation to organisational barriers was “*Its not a problem til it's a problem for the people who can fix it*”. There was a view that little could really be done in relation to formal changes to work hours or work practices. Of note was the acknowledgement of the community’s role in some work practices, including the expectation of continuity of carer. This is exacerbated by the view within teams or facilities that healthcare practitioners are not interchangeable, with obvious distinctions between specialities (e.g. anaesthetics versus obstetricians). Such obstacles are not, however, insurmountable (Landrigan et al., 2007, Dawson and Zee, 2005).

The limitations of the study should be noted. It is possible that respondents volunteered because they had experienced a fatigue-related error, and/or considered fatigue to be a significant problem in their workplace, or in general in the sector. The sample, as a result may not be representative of the general population. Further, the current design cannot give any indication of the prevalence of fatigue or fatigue-related errors in Australian healthcare facilities. Instead the findings describe the perceived causes and consequences of fatigue-related errors when they do occur, and most importantly, the fatigue management strategies used by healthcare practitioners.

In summary, healthcare professionals reported that work hours, scheduling practices and organisational culture influenced fatigue levels, work performance, health and well-being, and patient safety. More importantly however, participants identified specific error protection practices and fatigue-proofing strategies they use to manage the risk of fatigue-related error. These practices appear to have been tailored and tested in the local settings and are now part of routine, albeit, informal practice. The findings identify clear opportunities for the management of fatigue-related risk through two avenues – (a) reducing the likelihood of a fatigue-related error through appropriate scheduling, fatigue countermeasures such as napping, and workplace procedures that include error protection practices, and/or (b) reducing the consequences of fatigue-related error by developing error tolerant systems of work which catch errors before they become consequential. Tailored, evidence-based fatigue risk management programs that incorporate the ‘fatigue proofing’ practices developed by the experts on the wards and in the theatres represent a step-change in fatigue management in healthcare.

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Social Networks and Human Health in the Arctic

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ABSTRACT

The current paper introduces a social networks model as a way to understand arctic health through social networks, social capital, and social exchange. The paper argues that the Arctic is a unique place wherein social networks are formed within an environment of rapid sociocultural, political, and economic change. Though the Arctic is made up of varied geopolitical boundaries, governments, cultures, peoples, and histories, a unified arctic identity has been forged by cooperative international social networks. Though arctic health has improved over the decades, health statistics and research show that many health and behavioural problems are especially burdensome for arctic citizens. Arctic populations have been shown to disproportionately experience ill-health relative to their southern, non-arctic counterparts within their sovereign countries. In this paper, arctic health is viewed as important for all arctic people, indigenous and non-indigenous. The current paper suggests that socio-structural macro-level conditions can be linked with psychosocial micro-level mechanisms via social networks in the Arctic.

INTRODUCTION

Early research in arctic health was largely paternalistic in nature and favoured examination of logistical issues such as geographic isolation, harsh weather conditions, lack of physical infrastructure, and training of medical staff (World Health Organization, 1963; 1979; 1982). Contemporary research, however, has increasingly begun to consider the sociocultural aspects of health in the Arctic (*Arctic Human Development Report*, 2004; *Arctic Monitoring and Assessment Programme*, 2009). Although the social sciences generally have become more visible in arctic health research (Arctic Research Consortium of the United States, 1999), scant literature exists where social networks from a sociological grounding have been explored specifically within the Arctic. Even rarer is any integrated discussion of social networks and health for arctic populations. Young et al. (2012, p.135) write that 'the relationship between social networks [and health] is well established [but] data specific to circumpolar populations are not available.'

Arctic countries include Norway, Sweden, Finland, Russia, United States (Alaska), Canada, Denmark (Greenland and Faroe Islands), and Iceland. In the current paper, the arctic population includes both indigenous and non-indigenous persons. This approach is intentional because it allows for a transnational, human-centred view of the Arctic as a unique place wherein social networks and health are relevant for all social actors across individual, community, regional, national, and international levels. Indigenous persons account for only 5% to 10% of the total estimated 4 to 10 million arctic population though they represent the majority in Nunavut, Canada, Greenland, and parts of arctic Russia (Bogoyavlenskiy and Siggner, 2004; Young et al., 2012). Detailed considerations of what is indigenous and non-indigenous are impossible here, but see Coates (2004) for a comprehensive discussion on indigenous peoples generally. Population sizes of individual villages and cities vary. The largest metropolitan area in the Arctic is Arkhangelsk, Russia

with only 350,000 people (Russian Federation Federal State Statistics Service, 2012, p.471).

Arctic human health is concerned broadly with all people living in the circumpolar north. The arctic human health perspective taken in this paper embraces a holistic representation of health for the *entire* arctic populace. Such a view does not undermine the importance of indigenous health issues which stem often from poverty, discrimination, and rapid social change. Instead, viewing arctic health as a *human* phenomenon rather than singly an indigenous one refocuses the locus of health in a broader framework of arctic identity that may benefit all people residing in arctic place. Research has demonstrated that the standard social determinants of health (i.e., age, income, education, etc.) are related significantly to health outcomes in both indigenous and non-indigenous populations (Wilson and Rosenberg, 2002). Plus, targeting arctic indigenous peoples as sufferers of health conditions apart from the rest of the Arctic may unintentionally perpetuate false images of defencelessness and dependency. Thus, whilst strictly indigenous health issues remain a concern, basic public health problems can be addressed equally for all arctic residents irrespective of indigenous identification.

Why special attention to the Arctic?

Many social and health concerns prevalent throughout the Arctic have been discussed in key literature such as Andersen and Poppel (2002), *Arctic Human Development Report* (2004), *Arctic Monitoring and Assessment Programme* (2009), Bartlett et al. (2007), Bjerregaard (2001), Bjerregaard and Young (1998), Bjerregaard et al. (2004), Chatwood et al. (2012), Curtis et al., (2005), Kruse et al. (2008), Parkinson (2010), Waldram et al. (2006), Young (2008), Young and Bjerregaard (2008a), and Young et al. (2012). These topics include cold weather extremes and climate changes; underdeveloped living conditions and lack of infrastructure; toxic contamination of food and water sources; radical changes in diet, nutrition, and food security; and challenges in health care delivery. Although all arctic countries are well-developed [see United Nations Development Programme's Human Development Index (2013)], the key literature notes that rural and urban arctic populations experience a greater burden of the aforementioned concerns when compared with southern, non-arctic areas within their sovereign countries.

Recent statistics compiled by Young (2008) show that throughout the Arctic, both men's and women's life expectancy is lower in northern populations when compared to the respective country or state average. For example, the 2000-2004 average life expectancy of Alaska Natives in Alaska was 6.5 years lower for males and 4.6 years lower for females than of the whole state. In Canada, the largest gap in life expectancy is in Nunavut where males live 10.6 years less and females 11.3 years less than the greater Canadian population. In Greenland, men live 10.3 years less and women 9.2 years less than the average life expectancy in Denmark. Many arctic areas of Russia have lower life expectancies for men and women by as much as 10 or 11 years when compared to Russia as a whole.

Life expectancy in arctic Russia is dire (Kennedy et al., 1998; Shkolnikov, 1998). In Arkhangelsk Oblast, men die 15 years earlier than women. In Koryak, a male is expected on average to live only to 50 years of age. In arctic Russia, life expectancy rates can be lower than those found in some of the most impoverished countries of Africa, middle Asia, and the Asian Pacific (United Nations Population Division, 2011, table S.16, pp.122-126).

Infant mortality rates from 2000-2004 show higher values for most arctic areas when compared to respective national rates. Infant mortality is substantially high in Nunavut, Canada (15.3 vs. 5.3 national) and Greenland (12.7 vs. 4.7 Denmark). Within the Arctic, infant mortality is a pressing concern in most of northern Russia with the highest rates at

22.5 in Evenki and 20.3 in Chukotka. Of particular concern with infant mortality in the Arctic is the role of poor maternal health (Odland and Arbour, 2008).

Across various years, age-standardized mortality rates broken down by infectious disease are experienced disproportionately by Alaska Natives (19.8) relative to Alaska as a whole (11.5). Similar disproportions were evident in Northwest Territories (13.9) and Nunavut (20.7) when compared with Canada (9.1). The highest rates of arctic infectious mortality occur in Greenland (36.3) and Russia's Evenki (47.1) and Koryak (117.4). Transmission of infectious disease, including sexually-transmitted infections, remains a problem across much of the Arctic despite intervention efforts (Butler et al., 1999; Cruwys and Nuttall, 1992; Parkinson et al., 1999; 2008; Young et al., 2012; Zulz et al., 2009).

High rates of tuberculosis from 2000-2004 are found among Alaska Natives (35.3 vs. 9.7 state) and Nunavut, Canada (107.6 vs. 5.4 national), Greenland (137.5 vs. 8.4 Denmark), and Koryak, Russia (333.9 vs. 88.8 national). Resurgence of tuberculosis is a major problem for Alaska Natives, all of arctic Russia, Nunavut, and Greenland. Known risk factors such as diabetes, high immigration rates, and substance abuse help propagate tuberculosis throughout vulnerable arctic populations (Orr, 2011a; Parkinson et al., 2008).

Age-standardized mortality rates of deaths specific to circulatory, respiratory, digestive, and cancerous conditions illustrate a similar repeating pattern – many populations of arctic North America and arctic Russia share a greater burden of death relative to the nations of which they are a part. For example, the highest rates of all cancer deaths belong to Nunavut, Canada (378.9) and Greenland (358.8) with much of arctic Russia closely following. Circulatory diseases are a major arctic Russian health crisis where mortality rates are as high as 1,581.7 in Koryak. Epidemiologic transition in the Arctic is evident by increases in incidence and death for cardiovascular disease, Type II diabetes, cancer, and obesity which mimic similar health patterns of the industrialised West.

Epidemiology of injury death across various years in the Arctic shows higher rates when compared with national rates. Injury death occurrence is 15-20% higher in Finnmark, Norway; Norbotten, Sweden; and Lappi, Finland. Rate of death by injury is 38% higher in Alaska, 65% higher in arctic Canada, and 76% higher in Greenland. Injury death is widespread in arctic Russia where ten out of thirteen Russian geopolitical divisions report higher-than-national rates by as much as 47%.

Behavioural problems including suicide; alcohol, drug, and tobacco use; and family violence are significant public health issues in Alaska, arctic Canada, Greenland, and arctic Russia (Adelson, 2005; Bjerregaard et al., 2002; Lehti et al., 2009; Segal and Saylor, 2007; Shkolnikov, 1998).

As these statistics show, poor health throughout the Arctic is evident by low life expectancies, high infant mortality rates, high rates of infectious diseases, increasing rates of acute and chronic diseases, high rates of injury, and increases in behavioural problems. Although some segments of the Arctic are worse off than others, taken as a whole Young's (2008) statistics demonstrate that measures of many social and behavioural indicators for the Arctic are indicative of poorer health than the national statistics for the same indicators in the same countries. In general, the people of the Arctic continue to display substandard indicators of health and social development, and feature a mal-distribution of health resources, when compared with their fellow national citizens.

The Arctic is a unique place wherein a complex array of factors influences human health. Research already has found that place generally dictates 'health, illness, and preventative care [as well as] treatment rates, types, and outcomes' (Pescosolido, 2006, p.199). Despite

recognition that ‘the Arctic is considered as a specific geographic and cultural area’ (Csonka and Schweitzer, 2004, p.51), arctic studies have been slow to synthesise contextual and compositional place in the sociological sense (see Macintyre, 2004) as a distinguishing feature of arctic health. In a book review of Young and Bjerregaard’s (2008a) *Health Transitions in Arctic Populations*, Jacobsen (2009, p.1134) writes that...

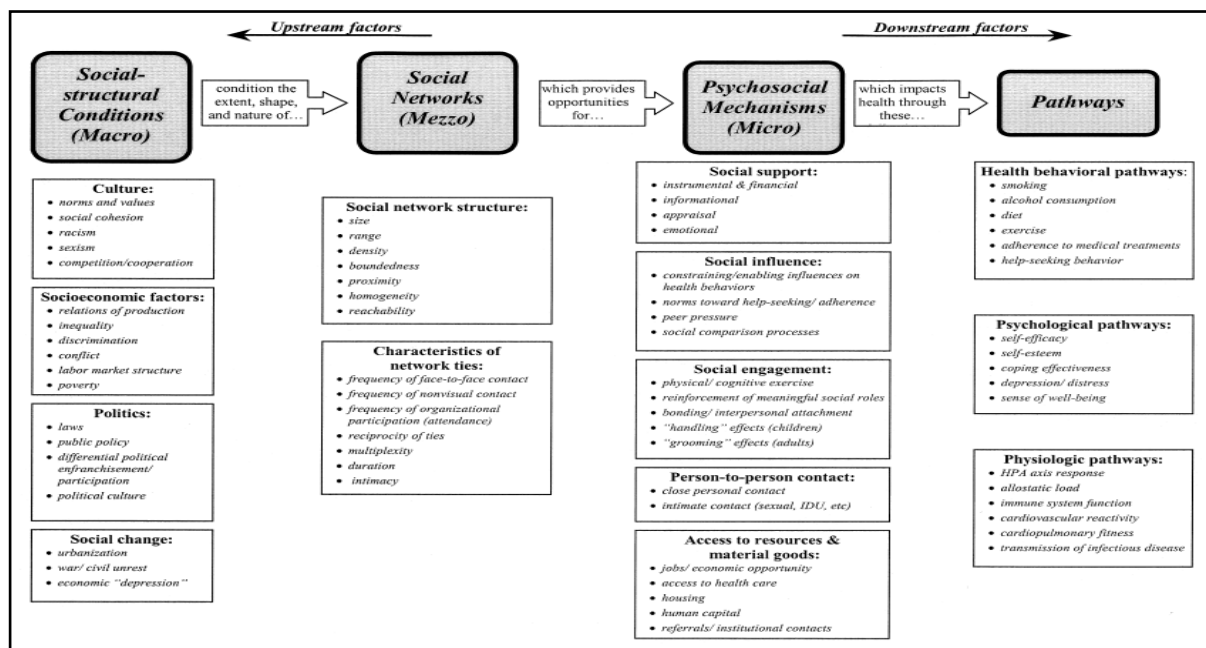
‘hundreds of books focus on tropical medicine, but almost none concentrate on health in the polar regions of the globe.’

This single quote underscores the pressing need for more studies and literatures on health, illness, and healing in the Arctic.

Berkman’s conceptual model

Berkman et al. (2000, p.847) and Berkman and Glass (2000, p.143) propose a model emphasising the importance of social networks in the health and illness context across multiple social, cultural, and behavioural structures. This model provides a thorough identification of the myriad factors affecting arctic human health. According to the model, the effects of social networks on human health are dictated by the structure and characteristics of the network, existing macro- and micro-level conditions, and both upstream and downstream factors. The model is reproduced in the current paper as Figure 1.

Figure 1 – Model proposed by Berkman et al. (2000) and Berkman and Glass (2000).



The model shows that health is largely dictated by social networks at the meso-level. These social networks are conditioned by existing macro-level social forces. Social networks, in turn, cultivate micro-level psychosocial mechanisms. Driven by social networks, these mechanisms impact health via behavioural, psychological, and physiological pathways. Running concomitantly alongside the macro-, meso-, and micro- components of the model are upstream and downstream factors further controlling how social networks affect health.

Social networks: Theory, structure, and characteristics

Although a comprehensive examination of social networks is beyond the scope of the current paper, a succinct definition of social networks is...

'the web of social relationships that surround an individual and the characteristics of those ties' (Berkman et al. 2000, p.847).

Ertel et al. (2009, p.74) define social networks as...

'aspects of the social environment that have to do with social relationships from intimate ties to more extended community ties and social engagement, participation, and social integration.'

According to Pescosolido (2006, p.194)...

'social networks provide the structural element of the mechanism of social interaction ... it is the structure and content of social networks that together shape and give meaning to context.'

Generally, research focused on the structure and characteristics of social networks (e.g., range, density, proximity, etc.) have found that these aspects fundamentally shape how and why social networks develop (Haines and Hurlbert, 1992; Seeman and Berkman, 1988).

Many types of social networks exist in the Arctic. *Kinship* and *family* have been well-recognised as a fundamental unit of social organisation across nearly all human societies and are important markers for arctic identity and livelihood. *Religion* – a set of beliefs about existence – also has long been a part of human activity in most all societies and is a prominent cultural element in arctic lifestyle. A sense of *community* and *citizenship* provide additional strata of social organisation and also are key elements of arctic identity. Kinship, family, religion, community, and citizenship have been discussed at length in the key arctic literature mentioned earlier.

Via social networks such as kinship, family, religion, community, and citizenship, social capital allows resources to be exchanged. Again, a thorough review of social capital is not possible here, but Bourdieu (1986, p.248) defines it as...

'the aggregate of the actual or potential resources which are linked to possession of a durable [social] network of... institutionalized relationships of mutual acquaintance or recognition.'

Schuller et al. (2000, pp.1, 35) defines it as...

'the reciprocities that arise from [social networks] and the value of these for achieving mutual goals ... [it] shifts the focus of analysis from the behaviour of individual agents to the pattern of relations between agents, social units, and institutions ... [it is] a link between micro-, meso, and macro-levels of analysis.'

Social capital makes up the features of social networks that facilitate or restrict the flow of resources; it is not the resources themselves *per se*, but those qualities and characteristics – for example, reciprocity, trust, friendship, altruism, expectation, frequency of contact, purpose, and intimacy – that assist in the production of resource delivery (Coleman, 1988; 1990; Kawachi and Berkman, 2000).

Much research has shown generally that lack of favourable social networks, capital, and support has deleterious effects on health outcomes (Berkman, 1985; 1995; Berkman and Syme, 1979; Bruhn, 2005; Cattell, 2001; House et al., 1982; Kawachi and Kennedy, 1999; Kawachi et al., 1997; Kennedy et al., 1998; Lomas, 1998; Seeman, 1996). Research on varying *types* of social networks indicates that 'better health is observed ... in [social] network types characterized by greater social capital, regardless of cultural setting' (Shiovitz-Ezra and Litwin, 2012, p.902), lending credence to the notion that social networks and capital are fundamental to health even when cultural environments vary.

Socio-structural conditions, social networks, and health in the Arctic

Recall from Berkman's model that the socio-structural macro-level conditions of culture, socioeconomic status (SES), politics, and social change influence social networks. All four of these are salient in the Arctic and have a major role in the current state of Arctic development, social networks, and health. The following is an integrated discussion of how these four elements have convened to restructure arctic social networks and health outcomes.

Ten years before Berkman's model, Berry (1990) proposed a model of acculturative adaptation directly applied to the arctic context that features some of the same elements. Although acculturation is less emphasised in the canon of social network literature, it nonetheless plays a pivotal role in understanding micro-level health effects brought on by macro-level sociocultural change. Wolsko et al. (2007) has shown that acculturation can negatively affect – but *enculturation* positively affect – health in the Arctic when traditional life ways, social networks, and community identities are altered.

Research examining social networks and health in the Arctic has been scant, but research with arctic and subarctic populations has come to similar conclusions (Elo et al., 2010; Mignone and O'Neil, 2005; Nuttall, 1992; Richmond, 2009; Richmond and Ross, 2008; Richmond et al., 2007). Community integration, participation, and close-knit social networks yield high social capital that result in resources exchange, including social support. Health-related problems occur less when positive social exchange stemming from favourable social networks is present. However, engagement of health-damaging and destructive behaviours are possible when there is mal-adaptation to life situations, including rapid sociocultural change, lack of positive peer social networks and resources, and impoverished material living conditions. Mostly for indigenous populations, social networks have been shown to foster a heightened sense of belonging, identification with traditional culture and activities, and social support that correlates with better health outcomes. Underscoring the importance of community, Berkman and Glass (2000, p.137) note...

'the degree to which an individual is interconnected and embedded in a community is vital to an individual's health and well-being.'

Young et al. (2012, p.134) recognise that in the Arctic 'there are many examples of how cultural beliefs and practices expose people to, or protect them from, disease and injuries, including dietary customs, childcare practices, religious rituals, migration patterns, kinship relations, and medical therapies.' That social networks exert influence over health in the arctic population is not unlike the existing evidence that social networks influence the health of the general population.

A social exchange framework (Molm, 2006) placed inside Berkman's model is helpful for considering arctic social networks, social capital, and human health. In an arctic context, the health of indigenous and non-indigenous citizens is dependent on negotiated and reciprocal exchanges of resources within same and across different groups. Out of these uniquely created social networks arise the social capital that allows resource exchanges to occur (Molm, 1994). One reason why behavioural health problems are numerous in the Arctic may be because breakdowns in positive social networks result in (dis)stress that yields unfavourable social exchange behaviours and ill-health. Research elsewhere has already shown that stress can negatively affect health and that social support can act as a buffer to stress. The development of social capital leading to resources such as social support is likely impeded when social networks fail creating a cycle of (dis)stress that is difficult to break. The social capital that encourages positive social exchange and favourable health for arctic

residents may dissolve due to the decay of social networks already made unstable by rapid, unfamiliar social change. In this way, a social exchange framework embedded within Berkman's model allows a possible way to understand why poor health in the Arctic is not random. Ill-health does not occur randomly (Bury, 2005; Link and Phelan, 1995; Wilkinson, 1996). Poor health in the Arctic may be explained partially due to opportunistic pathways dug out by stress, lack of social support, and other social factors as shown in Berkman's model that rely in many ways on social exchange activity occurring in uniquely arctic contexts.

A common arctic identity has risen out of increased social change and political activity between indigenous and non-indigenous governments and organisations. A heightened awareness of circumpolar commonalities and shared initiatives – termed *circumpolarity* (Johansson et al., 2004, p.181) – reverberates throughout the Arctic and has empowered arctic people to be collective actors on a global stage (Heininen, 2010). In the Arctic, 'indigenous and non-indigenous identities are converging' (Csonka and Schweitzer, 2004, p.64) into a pan-arctic identity encompassing the entire Arctic. As Young and Bjerregaard (2008b, p.3) note, 'a circumpolar approach to identifying common issues and developing solutions that transcends national borders has increasingly been adopted by national and subnational governments, indigenous peoples' organizations, as well as professional and scientific associations.' Research has yet to explore what a unified circumpolar identity means for the development of arctic social networks or how a sense of *being arctic* may affect health outcomes and experiences, but Berkman's model may hold a clue. The numerous social networks allowing arctic cohesion and cooperation will continue to intensify and converge as long as social capital promotes the amicable exchange of social resources such political self-determination, public policy inclusion, and improved socioeconomic conditions. Such social networks could be used as a proxy to analyse a circumpolarity phenomenon that links international macro-level socio-structural conditions with micro-level psychosocial mechanisms that result in new pathways of health in the arctic.

The future of Arctic health?

The arctic population is mobile and transitory, and this mobility is likely a factor for health outcomes (Snyder and Wilson, 2012). Some rural indigenous groups change arctic locations according to the seasons; winters on the coast and summers inland. In urban areas, residents move in and out of the city due to temporary but lucrative industry work in construction; engineering; fishing; forestry; oil, gas, petroleum, and diamond mining; tourism; and research (Glomsrød and Aslaksen, 2008). Native people have begun to emigrate out of the Arctic to embrace a modernised way of life where they have access to increased employment and education opportunities, improved healthcare, current technology, and other modern conveniences. Future arctic health research should examine how such population fluctuation impacts social networks and capital.

Embedded within an exploration of social networks and capital could be future community and public health studies that directly involve arctic peoples for research planning, implementation, and follow-up procedures. Active incorporation of arctic residents into community and public health studies would be beneficial because these types of studies 1) do not depend on passive dissemination of information to an uninvolved target audience, 2) have the potential to be highly empowering among both rural and urban circumpolar groups, and 3) allow researchers to better understand the unique health communication needs of and best health practices for the arctic populace. Some studies already have recognised the importance of including arctic residents in developing local community, public health, and well-being initiatives (Bjerregaard et al., 2008; Orr, 2011b; Wilson and Young, 2008). The practice of involving the arctic population in their community and public health care

education, communication, and delivery should continue and become even more sophisticated. Future programmes seeking to expand health resources into the Arctic will be wise to encourage the cultivation of strong, collaborative social networks within parameters that are supported by the people for which they are intended. Future arctic health programmes also should employ models that create optimal conditions for enabling favourable health behaviours that are aligned with the realities of living in the Arctic.

Following Waldram et al.'s (2006, pp.122-124) call for life-course perspectives in indigenous health research, life-course approaches should be considered for all arctic populations. A primary benefit of using life-course as a conceptual synthesiser in arctic health research is that it could take into account longitudinal influences across the lifespan rather than only at a cross-sectional point. Some people live in the Arctic all of their lives, whilst others migrate in and out of the Arctic. Employment of life-course perspectives may yield a greater understanding of long-term social network and capital development along with their relationships to health resources and behaviours throughout one's life.

Finally, given the current arctic Russian health crisis (Young, 2013), new social and health data for and research on this area are needed due to geopolitical boundary changes that have occurred since Young's (2008) compilation.

CONCLUSION

Berkman's model provides a conceptual vehicle for the analysis of health through social networks. Within Berkman's model, a social exchange framework can help identify many positive resources such as social support and circumpolarity, as well as unhealthy stressors such as weak social ties and propensity to engage in unfavourable coping behaviours. The current paper has introduced a social network model to begin understanding how macro- and micro-level forces might influence health in the Arctic, and how those social networks depend on social capital and resource exchange in the highly diverse and volatile arctic environment.

In general, arctic people are living longer and healthier than they have in the past. However, data presented in this paper show that serious health issues in the Arctic are real and in need of attention. At the macro-level, the Arctic has been affected by global changes in culture, politics, and society. At the micro-level, resources such as social support, community involvement, and cultural identity are shown to be important for much of the arctic population. The social networks of Berkman's model stimulate the pathways of social capital and resource exchange between these macro- and micro-level events toward human health outcomes for all arctic citizens.

The specialty of 'arctic health' – that is, the study of health, illness, and healing in the Arctic for all people and groups – is still a relatively new area of inquiry. Sociology is poised to add to the discourse on social networks and capital in the outcomes of health occurring in arctic place.

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Crisis and Renewal in Irish Public Health: Analysis of a Neo-liberal State

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ABSTRACT

Approaches to health in Ireland have been traditionally based on the curative biomedical model, with public health infrastructure underdeveloped and typically focused on the treatment of disease rather than its prevention. Based on three papers presented at the Critical Issues in Irish Society Network conference (2012) 'Health in Crisis', this article explores to what extent Ireland is moving towards addressing the broader social structures which both enable and constrain health and wellbeing. It will argue that despite isolated examples of patient-centred approaches to care, a less atomised and more holistic understanding of the treatment of illness is required in Ireland. Similarly, Ireland's record on addressing the wider social determinants of health (SDH) through specific public policy measures, even when compared with similar liberal welfare regimes (UK, Australia and Canada) remains poor. While a strong evidence base on the SDH has emerged in Ireland in recent years, the historical weakness of the welfare state, in combination with the present day dominance of neo-liberal governance, means that specific policy actions remain subordinate to an individualised approach to health promotion. It will conclude by arguing that in countries such as Ireland where there is a significant absence of political will to address the SDH, the need for a 'public sociology' which raises awareness of the relationship between class, inequality and health to audiences outside of the academic and political spheres is critical.

INTRODUCTION

The social determinants of health (SDH) is a concept that is ubiquitous in health related government policy documents worldwide. However, there are vast differences between countries in the interpretation, understanding, and implementation of SDH policies (Raphael 2012). This article examines to what extent a holistic, social determinants of health (SDH) model for both the treatment and prevention of illness has been discussed, debated and implemented in a country with little tradition of public health, and which has been strongly influenced by the political philosophy of neo-liberalism (Kirby 2010). In particular, it will examine to what extent the Irish state has addressed the key elements of the SDH model. It will argue that although there is some recognition of the SDH model in key policy documents, it has yet to be prioritised in policy and practice.

In order to carry out such an appraisal, the Conceptual Framework for Action on the Social Determinants of Health provided by the World Health Organisation will be used to assess the Irish states performance to date (Solar and Irwan, 2010). The authors identify social, economic and political arrangements as key mechanisms in determining health outcomes along class, gender and ethnic lines. Of critical importance are policies which affect the distribution of wealth and power in a given society, including in areas such as taxation, employment, housing, education, health and social protection. Unlike other SDH models

which have traditionally downplayed the role of the health system as a tool for addressing health inequalities, the report suggests that universal access to services plays an important role in minimising the consequences of illness, thus ensuring that those occupying lower low income groups are not further disadvantaged through disability or other health related barriers to participation in society. Furthermore, it argues that services should be organised in a non-hierarchical and person-centred manner as possible. In order to achieve such a pro-equity service, the WHO has indicated elsewhere that a holistic approach must be taken which encompasses of the social, psychological and spiritual whole (WHO 2007). This has been emphasised also in the Commission on the Social Determinants of Health 2008, the 2011 Rio Political Declaration on Social Determinants of Health and the EU report, Europe: Health 2020.

In addition, the theoretical frameworks in this paper will also be informed by more sociologically oriented theories of public health approaches to health inequalities, which at its core examines the social forces which shape economic and political arrangements which Irwin *et al.* (2010) identify as essential in determining health. This requires analysis of the historically disproportionate influence which elite members of society have over both policy making and governance, and its possible role in the generation and perpetuation of health inequalities (Scambler 2012; Raphael 2012; Muntaner 2011; Coburn 2004). In this respect Scambler argues the health inequalities research agenda should be critically focused not on whom it harms, but more on whom it benefits (Scambler, 2012).

This article firstly will provide a brief overview of the history and current state of public health in Ireland. It will argue that the underdevelopment of the Irish public health system can be explained by the absence of a left-right divide in Irish politics; the historical strength of the Catholic Church and medical profession in defining matters around health, as well the contemporary influence of neo-liberalism. The main section will then proceed to draw upon the works of three academics who presented at the Critical Issues in Irish Society Network (CIISN) conference. This article challenges researchers and policy makers to analyse critically and creatively about new directions and priorities needed in the field of health research in Ireland. Finally, this article will analyse the current predicaments and future directions in Irish public health research.

The CIISN conference 'Health in Crisis' was held on April 19th 2012, which was convened to provide a platform for the latest research examining the relationship between society, health and well-being in the context of Ireland.¹ The event was part of a wider initiative started by PhD students based in the UCD School of Sociology which aimed to address the lack of opportunities for early stage researchers in the field of sociology and similar disciplines to network, connect and exchange ideas. The objective of the 'Health in Crisis' conference was to encourage multidisciplinary dialogue in relation to health, wellbeing and society while still retaining a sociological focus. Although the papers were diverse in scope, when discussed together they formed a coherent narrative on the current state of the health of the population in Ireland. Discussions at the conference revolved around two main themes: firstly, to what extent Ireland is moving away from the traditional biomedical model, and secondly to what extent is Ireland addressing the wider social determinants of health. In order to examine to what degree these changes are occurring, this article will draw on three papers presented at the conference. These papers were chosen on the basis that they provide particular insight into some of the successes, and challenges, which face the public health system in Ireland.

The first paper delivered by Peter Kearney, '*The Barretstown Experience: a healthy response to crisis*' highlights an example of a successful holistic approach to paediatric therapeutic care in the context of Ireland and Europe. The second paper, '*Reforming Health Production*

in Ireland' presented by Prof Eamon O'Shea, discusses government proposals for equity within the health care system and questions whether this may lead to reductions in health inequalities across the population. The third paper '*Inequalities and Men's Health? Turning the policy spotlight on men*' presented by Dr Noel Richardson assesses the intersection between economic inequality and gender in the context of men's health and possible policy prescriptions. Drawn together, these papers present a snapshot of the current research landscape in Ireland. Before approaching this question however, it is first necessary to briefly discuss the historical and contemporary reasons why public health has remained underdeveloped relative to other rich market based democracies.

Historical Factors Constraining the Irish Public Health System

Ireland has been noted as having a severely underdeveloped and under-sourced public health system (Burke 2011). The medical and social historian Dorothy Porter has pointed out that most public health systems in Europe developed under the backdrop of a 'collectivist political will' which 'promoted increased state intervention in the provision of welfare in industrial societies' (Porter 1999:239). However, as Barrington (1987) noted the development of public health provision in Ireland was socially and politically determined through the power of the Catholic Church and the medical profession; both of whom from the earliest juncture in the formation of the state were ideologically opposed to the intervention of the state in matters related to health.

One of the defining moments in this regard, was in 1951 when the then Minister for Health, Dr Noel Browne, proposed The Mother and Child Scheme (Barrington, 1987). The proposal, which sought to provide free medical maternity care for all mothers and free healthcare for all children up to the age of sixteen, regardless of income, represented the first major step-up in the state's role in public health in Ireland. The plan was however opposed by the Church hierarchy, who viewed the scheme as contravening the papal principle of subsidiarity, which stated that welfare was first and foremost the responsibility of the family, church and voluntary organisations rather than the state (Whyte 1971). It was equally opposed by the Irish Medical Organisation who saw it as a threat to private practice, and a stepping stone towards socialised medicine, similar to the establishment of the NHS in the UK. A long and protracted confrontation between the state and these two interest groups eventually led to the defeat of the bill, leading to the resignation of Noel Browne and strengthening the role of the private practice and the voluntary sector in the provision of healthcare.

While the state eventually did start to expand its role in the health of the Irish public during the 1960s and 70s, it did so largely under the parameters set out by the Catholic hierarchy and the medical profession; both of whom blocked any move towards universality in the provision of care. Thus even as free hospital care was gradually extended, by means of general taxation to include 75% of the population, private practice remained an entrenched feature of the Irish health system (Barrington, 1987). This was cemented further with the establishment of the Voluntary Health Insurance (VHI). A significant consequence of these concessions made to both the Catholic Church and the medical profession, was that public health infrastructure remained underdeveloped, minimal, and confined to the treatment of disease rather than its prevention. Health was not perceived as an inalienable right, to be guaranteed through various interventions of the state, in the traditional social democratic sense seen in other European countries (Porter 1999), but as an issue of personal responsibility. The 1980s and 1990s bared witness to the diminishing role of the Catholic Church and to a lesser extent the medical profession who lost credibility in the face of treatment related scandals. For example, the Irish hysterectomy scandal, where between 1992 and 1988 the rate of hysterectomies in Our Lady of Lourdes Hospital Drogheda was 20

times that of other similar hospitals; Dr Neary's gynaecological patients were subjected to unnecessary hysterectomies and/or oophorectomies (McCarthy *et al.* 2008)

However, the emergence of neo-liberalism as the dominant political ideology in the state began to fill the void left by the Catholic Church, hence ensuring that an individualised approach to health and well-being among policy makers in Ireland remained firmly intact (Burke, 2009; Wren, 2006).

Throughout the early 2000s, there was an increased rhetoric for the need for an equitable and holistic approach to health (Department of Health, 2001). However, even during the economic boom of the 'Celtic Tiger' inequities in access to care remained entrenched, and although funding was greatly expanded to the acute care sector, primary and community care remained underfunded, with access dependent on means. With Ireland in economic crisis, the current governing coalition of Fine Gael and Labour have now acknowledged the need for social solidarity, where 'reform is no longer just an aspiration for Irish health care – it is now an essential' (Labour 2010:2). The Irish government now view Universal Health Insurance (UHI) as a means for not only insuring equity and health for its citizens, but also to provide good quality care for all of its citizens.

Challenging Reductionist Medicine in the Irish Health Care System

The 2001 Health Strategy in Ireland (2001:187) pointed out the necessity for the 'provision of holistic and seamless services' within the health system. Deficiencies in addressing these have led the Irish public to seek alternative methods of care through voluntary organisations such as Barretstown. A clear departure away from the traditional biomedical model towards holistic, patient-centred care can be seen in Peter Kearney's research paper on the Barretstown Experience, which he argues is an example of a successful approach to holistic care in Ireland. The Barretstown Castle Holiday Camp is a specially designed camp that provides therapeutic recreation programmes for seriously ill children (primarily cancer and serious blood diseases). Barretstown was founded by the late actor Paul Newman as part of the Serious Fun Children's Network, the first camp of its kind in Europe, catering for over 1,500 children per annum. Although the premise of Barretstown Castle was donated by the Irish Government, it is operated on a completely voluntary basis and is funded without state support. The Barretstown experience according to Kearney may be seen as a step towards a more holistic and patient-centred approach to health and well being, breaking down the boundaries between doctor and patient, by creating a non-hierarchical structure with voluntary and non-uniformed health professionals, trained specifically in therapeutic care. Critically, health professionals are not referred to by their status, rather to as a *Cara* (Gaelic for friend). Kearney goes on to argue that the core values of 'serious fun' represent an experience that is in many ways opposite to the rationalised and medicalised world in which children normally experience treatment for serious illnesses.

For Kearney, Barretstown is a social and psychological transformation, with profound improvements in health outcomes for children. During their stay at Barretstown, children are temporarily removed from the norms, expectations, and stigmas that predominate in the broader social and cultural environments in which they live. Instead a temporary community of equals is created, giving the child the psychic-space in which to come to a sense of coherence and self-identity; which is not impinged by social stigmas surrounding illness.

Kearney presented evidence that children have an improved sense of coherence after camp, which enables them to cope better with the demands of ill health. Kearney linked this 'sense of coherence' theoretically with Antonovsky's (1979) concept of salutogenesis, a 'specific way of viewing life as comprehensible, manageable and meaningful' claiming that the way in

which people relate to their life influences their health (Eriksson *et al.* 2007:684). Barretstown caters beyond the treatment of the disease, where within the sphere of fun and engagement, the situations of predictability or unpredictability enable the child to learn to adapt and maintain stability. In evaluating research on serious chronic illness to date, Kearney noted how emphasis lay with poor self-esteem and self-image, rather than questioning the possibility of the patient exceeding expectations and engaging with life. This indicates the importance of drawing to the SDH and holistic care within the treatment of illness, which is supported by the success of Barretstown in both achieving a sense of coherence among children. As far back as 2001, the Irish government placed the importance of providing a holistic approach as a core value of their Health Strategy (2001). Despite being a successful example of a holistic and patient-centred approach Barretstown remains an isolated case, completely separate from the rest of the health system in Ireland.

Challenging the Individualised Approach to Irish Public Health

The conference heard from Professor Eamon O'Shea (School of Economics NUIG) that interest in health in Ireland has predominantly revolved around the healthcare system, and not enough on the wider social and political determinants of health. This, he asserted is to some degree understandable given the deep inequities and inefficiencies that have been a feature of Irish health services for many years. However, he argued that there should now be a concerted effort to increase government awareness of the need to take action on the SDH.

O'Shea began his paper by pointing out that there *have* already been significant attempts to put the health inequality agenda on the map in Ireland. The Irish Institute for Public Health (IPH) for example, have been prolific in publishing numerous studies documenting the close relationship between socioeconomic status and health on the island of Ireland (Balanda & Wilde, 2001; Dillon, Paul, Metcalf, & Cotter, 2011; McAvoy, Sturley, Burke, & Balanda, 2006). These studies have highlighted the poor health outcomes and relatively lower life expectancy of deprived communities which have benefited little during the Celtic tiger era, now bearing the brunt of the country's economic recession. In recent years, the Combat Poverty Agency and IPH produced the policy document, *An All Ireland Approach to Social Determinants* (Farrell, McAvoy, & Wilde, 2008), which outlines a range of evidence based interventions which could be adopted to improve health inequalities. This coupled with the independent think-tank TASC report, *Eliminating Health Inequalities: A Matter of Life and Death* (Burke & Pentony, 2011), provides a significant blue print which government could follow in order to improve population health. Recommendations by TASC, for example include proposals for an independent review of health inequalities modelled on the UK Marmott review *Fair Society, Healthy Lives*, which would form the basis of future population health policy in Ireland (Burke & Pentony 2011:vii), and additionally aiming to increase social spending in health and education through higher taxation. However, despite having garnered support from a number of key stakeholders, including the Irish Medical Organisation (2012), the Irish political establishment have yet to signal intent to adopt any of these recommendations. This is in contrast to other western countries, where attempts at tackling health inequalities have occupied the political agenda for decades (Raphael, 2012).

O' Shea viewed recent debates around inequities in the Irish health care system as being particularly illustrative in this regard. He highlighted that over the last number of years there has been increasing media attention and public pressure to bring to an end the provision of care based on a public-private mix; which enables holders of private health insurance speedier access to treatments than those who enter the healthcare system as public patients. In 2011, the Fine Gael and Labour parties were elected to government, promising to abolish Ireland's two tier health system and replace it with the Universal Health Insurance

model, similar to services currently in place in the Netherlands and Belgium (Fine Gael & Labour, 2011). O'Shea noted that while equalising health outcomes across the population was a core objective of these reforms, discussion of the wider SDH was notable only in its absence. Citing Burke and Pentony (2011), he observed that the vast majority of the Department of Health budget remains focused on acute, technology-driven medicine, and little attempt has been made to coordinate with other government departments to make investments in health across the population.

A particular problem O'Shea observed is that other government departments view responsibility for health as entirely beyond their remit. For example, little awareness is demonstrated that improving peoples' material living conditions through investment in social welfare and other forms of wealth redistribution could lead to substantial health gains in the long run. The consequence he argued is that Ireland is comparatively:

some distance away from addressing the broad life course determinants of health through active health policy interventions outside of the health care sector (O'Shea & Connolly, 2012: 1365).

O'Shea therefore called on key stakeholders and policy makers to take a broader view of health which takes into account material living conditions, and to enact interventions which would lead to

Equalising opportunities for health across the life course, an essential component of maximising health production' (O'Shea & Connolly, 2012: 1365)

O'Shea concluded by arguing that a cost-benefits analyses approach could be particularly useful in persuading government of the clear economic rationale for addressing the SDH, which he argued would lead to long term savings through reductions in demand for acute services and hospitals.

Barriers to SDH Implementation

The lack of action on SDH in Ireland was further discussed in a paper presented by Dr Noel Richardson, Director of the Centre for Men's Health in Carlow IT. There has been a surge of interest in men's health in Ireland in the wake of unprecedented increases in the number of suicides among young men (Dillon *et al.*, 2011). The vast majority of these cases are among lower socioeconomic groups where the collapse of local industries, high levels of long-term unemployment and lack of opportunities have had a significant impact on mental well-being (Dillon *et al.*, 2011). Whilst these problems are structural in nature and more than likely cannot be addressed without significant government investment in these areas, public health agencies attribute men's relatively poorer outcomes to individual behaviours and attitudes.

Richardson argued that men are predominantly framed as being risk takers who engage in practices which endanger their physical and mental well-being, and avoid seeking out help where support or treatment is required. Indeed much of the public health response has been predicated on media information campaigns raising awareness of the importance of self-help behaviour among young men, and in particularly confiding in family and close friends when experiencing emotional distress. Richardson noted however, that men already have a more multifaceted and complex understanding of the notion of responsibility for their own health than these dominant views suggest. In a qualitative study carried out on the beliefs and health practices of men in Ireland, Richardson observed that men were largely aware of having a duty of care towards their own health, to engage in the 'right' health practices, and to act as a 'responsible' citizen (Richardson 2010:423). At the same time, some of these men also rejected top-down health promotion messages and knowingly engaged in risky behaviours, often viewing the notion self-care as intrinsically effeminate. Their rejection was

seen as a form of principled resistance which gave them a way of reasserting a feeling of control and independence in their lives.

Richardson placed the emphasis on individual responsibility in government responses to the 'crisis' among young men within the context of the hegemony of neo-liberalism in Irish political discourse. Drawing on a Foucauldian perspective, he argued this can be seen as part of a wider process of the state attempting to further reduce its role of guaranteeing rights and entitlements for health by transferring responsibility to the individual. He argued however that the attitudes and behaviours of men cannot be viewed in isolation from their social and economic living conditions. Instead men's health outcomes could only be improved

by challenging the institutions in which men live and work, and by giving due consideration to the social determinants of health (Richardson 2010:434).

The conference heard how Richardson had become involved in the drawing up of a men's national health policy, with the explicit objective of moving the debate around men's health in Ireland away from these victim blaming tendencies. He was one of the co-authors of the *National men's health policy 2008-2013: working with men in Ireland to achieve optimum health & wellbeing*, the first of its kind in the world (Richardson & Carroll, 2008). However, despite being in a position of influence around policy formation in this area, evidence that Richardson was able to get SDH prioritised by government was mixed. Thus, while the report acknowledged 'that social and economic factors, including poverty are key determinants of the health status of men'(Richardson & Carroll, 2008:2), it failed to outline any recommendations on structural level interventions which government could take to improve the living conditions of men. Instead, the report noted the importance of challenging males to better look after themselves, with actions based around recommendations such as targeting

the home as a setting for enabling men to take greater responsibility towards their own health (Richardson & Carroll, 2008:9).

Richardson cited Ireland's unfavourable economic climate as reasons why perhaps a more radical approach to addressing the SDH could not be sought after and argued the development of men's health policy must dovetail 'with existing policy across different government departments' (Richardson & Carroll, 2009:112).

Possibilities for SDH Implementation

As the accounts of Kearney, O'Shea and Richardson have shown, discourses around the SDH remain largely aspirational in tone. This does not just apply to men's health policy, but across all policy related to health and well being in Ireland. For example, the national health policy documents on diabetes (Diabetes Expert Advisory Group 2008) and on cardiovascular disease (Department of Health 2010) both recognised income inequality and the SDH as the most significant factors in driving increasing rates of chronic conditions in Ireland. However, these reports give no explicit recommendations on how to address SDH; instead they focus almost exclusively on individual level interventions such as education around healthy eating, and programmes which encourage frequent exercise and smoking cessation. The 2005 report on 'Obesity: the policy challenges' (Treacy 2005) gives more recognition to the constraining effects of poverty by recommending increasing social welfare benefits in order to enable individuals on low incomes to make healthier food purchases. However, interventions to prevent obesity were discussed largely within the context of fostering individual responsibility for personal lifestyle choices. This tendency to extol the importance of the SDH at the outset of health related policy documents, only to fall back on an individualised behavioural approach in setting out key recommendations, interventions and targets, is not unique to the policy formation in Ireland. 'Lifestyle drift' as Marmot calls it

(Popay *et al.* 2010:148), is a predominant feature of policy documents related to health inequalities in countries where there is a strong neo-liberal emphasis in public policy prevails (Raphael, 2012).

However even when compared to other liberal welfare regimes such as the UK, Australia, and Canada, it is possible to argue that Ireland's performance relating to specific public policy measures aimed at addressing the SDH has been poor. As O'Shea alluded to, bold reforms have been proposed with respect of introducing equity in access to Irish healthcare system in recent years. However, equalising opportunity for health outside of the healthcare system through investment in early childhood welfare programmes for example, have been largely left off the table. This is in contrast to other liberal regimes such as UK and Australia, where despite having undergone significant welfare state retrenchment, governments have still undertaken policy initiatives to tackle health inequalities, with various degrees of success (Raphael, 2012) In addition, Houghton (2005) has noted Ireland's exceptionally poor record in the funding of the monitoring and evaluation of health inequalities, with official publications becoming increasingly sparse in detail and often out of date.

Perhaps the most significant attempts in Ireland to address the SDH in line with UN declarations occurred during the Celtic tiger years through the implementation of the National Anti-Poverty Strategy (NAPS), between the years 1997 to 2007. In 2002, the government included explicit objectives in NAPS to reduce health inequalities in cardiovascular disease, cancers and low birth weights by at least 10% by 2007. Although these targets could again be considered comparatively conservative (Houghton 2005), the implementation of NAPs had some favourable outcomes. There is evidence for example that some wealth redistribution in the form of increased social welfare payments targeted at those on the lowest income gave rise to reductions in levels of absolute poverty and (to a lesser extent) relative poverty. The OECD have argued that because of this, the prevalence of inequality in Ireland during the Celtic Tiger years may have remained static, although still above the OECD average (Organisation for Economic Co-operation and Development, 2008). However, because of the lack of monitoring and evaluation systems, there is little knowledge of whether any targets on reducing health inequalities were achieved (McAvoy, 2008)

It is also important to note that throughout the Celtic Tiger, with the exception of NAPS, successive governments remained profoundly neo-liberal in their philosophical and ideological outlook, operating a programme of minimum state intervention, increased privatisation and de-regulation. Irish social and economic policy was based on a low tax model rather than a more progressive taxation system as exemplified among the Nordic countries and to a lesser extent the UK and Australia. Thus in order to fund increases in social welfare, the Department of Finance was reliant on accumulating revenue through unsustainable levels of economic growth, which was in turn fuelled by a speculative bubble in the property and construction sectors. Consequently when the Irish economy officially went into recession in 2009, these social welfare increases could no longer be sustained (Kirby 2010). Austerity measures introduced in response to the subsequent fiscal collapse included significant reductions in social welfare benefits, as well as a raft of stealth charges and increases in indirect taxation. This coincided with a steady increases in income inequality in subsequent years (Central Statistics Office, 2013).

Recent debates within sociology have suggested that those working in the fields of the SDH have often been too focused on consequences of income inequalities to the detriment of understanding its broader structural antecedents and causes (Coburn, 2004; Scambler, 2012; Wilkinson, 2000). Coburn (2004) has highlighted the importance of looking beyond the

surface effects of income inequality on health, to focusing on the ideological and political power structures which continue to justify, and thus ultimately serve to reproduce them. Here he identifies the influence of neo-liberalism in public policy, which he argues increases elite groups control over economic resources in society; as a key mechanism which exacerbates income inequalities and consequently, health inequalities. He views political configurations and 'historically embedded variations in class and institutional structures,' as being a significant factor in whether a country is more likely to adopt or resist neo-liberal reform (Coburn 2004:41). Hence countries which have a history of electing social democratic parties tend to be more concerned and have more success in addressing the SDH (Raphael 2011a), than in countries where conservative governments have spent a greater proportion of time in power. In Ireland, the absence of class based politics and the weakness of a left-right divide, as well as labour and trade union movements, is reflected in the fact that the state has never witnessed a majority left wing government (Mair 1992). This could in part explain why references to addressing health inequalities in key Irish health policy documents have remained as mere window dressing.

Consequently, it could be argued that while the Institute of Public Health in Ireland, as well as academics such as Eamon O' Shea and Noel Richardson, play a significant and necessary role in bringing to the attention of government issues surrounding the SDH, it is unlikely that the sheer weight of evidence they present will generate a fundamental shift in understanding how population health is understood. Furthermore, it appears that an individualised view of health is so historically and culturally embedded in the Irish context that any proposals which call for fundamental wealth distribution are likely to be disregarded. This is compounded by Ireland's current economic crisis and cut-backs across all government departments. However, even in the context of the economic downturn and the constraints of the EU-IMF bailout programme, there is still manoeuvrability around political choices and fiscal matters which ultimately determine who will bear the brunt of the recession in society. Those working within the SDH framework in Ireland may need to find new strategies in challenging the government to follow through on the full implementation of SDH.

This lends itself to the recent work of Scambler (2012), who borrowing from Buroway (2005), has suggested that a 'public sociology' around health inequalities which engages with communities outside of the traditional academic and political sphere is essential. It is likely that only through drawing attention to the Irish public of the profound impact that political choices have on their health and well being, that there will be any real and substantive action on the SDH.

A crucial part of this public sociology, Scambler asserts is studying 'upwards' and bringing to light those who benefits from such inequalities; his provocatively named 'Greedy Bastards Hypothesis' seems particularly apt in the context of Ireland:

widening health inequalities can be reasonably regarded as the unintended consequences of [a]...weakly globalised power-elite informed by an increasing irresistible, voracious and 'strategic' appetites of core members of its (strongly globalised) 'capitalist-executive'. (Scambler 2007:305)

As the TASC report on health inequalities has pointed out, the disproportionate influence which business leaders, financial institutions and property developers had over the economic policy arrangements of the Irish state had a significant role to play in its eventual economic collapse. Although these issues are well-known within the public domain, there is less awareness of their significance in shaping both quality of life and life expectancy. Exploring the link between the disproportionate influence which elites' have over the economic and political institutions of the state and outcomes for population health will ultimately be a crucial

component of this public sociology in Ireland.

This article has argued that a holistic approach to healthcare and the SDH model more generally have been largely neglected in Ireland, and in line with recent debates around the subject, there is a need for a public sociology which raises their profiles. However, in order to achieve this it is necessary to first find appropriate communication outlets for raising awareness among the public. As has been shown in other countries, where neo-liberalism is the dominant political philosophy, the mainstream media (Raphael, 2011b) is unlikely to support this process of raising awareness of issues around the SDH, and will more than likely continue to uncritically equate health with lifestyle choices. It will therefore fall to alternative media sources to inform the public of how the social structures in which we live affect health outcomes. For example, in Canada, a country which has also undergone neo-liberal reforms, a simple-formatted booklet, *Social Determinants of Health: The Canadian Facts* (Mikkonen, J et al. 2010) , proved hugely popular and disseminated widely among universities, public health institutions and high schools. It is important to note also that while the Irish population have been relatively acquiescent compared to other counties undergoing severe austerity programmes, there are examples of pockets of resistance and protests which have take place across the country(Allen 2011:80). Importantly, many of these protests have taken place around the threats of closure of local public hospitals, the end of universal access to primary care for the over 70's, as well as cuts to home care and community services, indicating that people can often be highly mobilised around issues related to health and wellbeing. In a neo-liberal state such as Ireland, the need for those working within an SDH framework to increase public awareness of the link between unjust social structures and their consequences for health, is a critical component in influencing the future direction of policies which shape population health.

Both authors contributed equally to this article.

¹ The conference was held in association and sponsored by the School of Sociology (UCD) and the Social Science Research Centre (UCD).

The committee (Carol Ellis and Shane O'Donnell) selected four areas as a basis for organising the conference programme; mental health, public health, live events and healthcare. The conference was chaired by Dr Ronnie Moore (UCD) and delivered in four phases, where each thematic area was delivered as a block with questions asked at the end of each session. Eleven papers were presented at the conference: Sarah Gibney (UCD), Darach Murphy (DIT), Dr Noel Richardson (CIT), Robert Mooney (ARC), James Fullham (UCD), Dr Ingrid Holme (UoS), Peter Kearney (UCC), Catherine Lynch (NCAD), Marcella McGovern (UCD), Maria Wegrzynowska (DCU), and Prof Eamon O'Shea (NUIG), where each paper contributed towards this paper, and we regret that they all could not be included in this paper, but thank everyone for their participation. With special thanks to Prof Tom Inglis, Dr Aogan Mulcahy, Veronica Barker, Dr Kieran Allen, Dr Michael Punch and Leon Dempsey.

For more information please see <http://ciisn.wordpress.com/>

² Inclusive of the Republic of Ireland and Northern Ireland

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Autistics speak but are they heard?

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Erratum Notice - A previous version of this article wrongly implied that Michelle Dawson is a self-advocate or autistic self-advocate, that she is part of self-advocacy movements or has similar views, and that she is academically trained (rather than being a researcher within a university-based research group). These have now been corrected, and we regret the errors.

ABSTRACT

In this article, we argue that the exclusion of autistic people from meaningful involvement in social scientific research is both ethically and epistemologically problematic, and constitutes a significant barrier to impact. By the term 'meaningful', we refer to the inclusion of different autistic voices not merely as sources of empirical material, but as active participants in the production of knowledge on autism. We discuss two trends in research that are of concern: firstly, the failure to explore and engage fully with the lived experiences of participants in social research; secondly, imposition of problematic narratives on autistic experiences, linked to partial or complete absence of engagement with the diverse work of autistic authors. We conclude by pointing to some contemporary developments and intellectual exchanges that serve as exemplars which increase the ethical and epistemological integrity of research on the lived experiences of autistic people.

Keywords: Autism, participation, wellbeing, exclusion, research ethics.

INTRODUCTION

The majority of published research in autism has emerged from areas allied to clinical practice; a consequence of which has been an almost exclusive focus on the condition as involving only deficits. While there are indications (Baron-Cohen et al., 2009; Mottron et al., 2006), that this is beginning to change - and that an appreciation of autism as involving a range of potential strengths and limitations is emerging - the view that still dominates mainstream research is that of autism as consisting exclusively of deficit. This has a range of implications: one of which is the exclusion of autistic voices from processes of knowledge production. We argue that this produces ethical and epistemological problems that are interrelated, such as the tendency to pathologise behaviours that may be seen as 'bizarre' or 'strange' to the observer without exploring their subjective rationale. In addition, there is also a lack of exploration of variation and contingency in the lives of autistic people (in particular adults), which stifles the development of more ecologically grounded understandings of autistic people's lives. However, some emerging developments in research participation may help overcome these limitations, and these are discussed in the final section of the paper.

Framing Autism

Autism Spectrum Conditions are commonly understood as involving difficulties in social communication, social interaction, and social imagination (Baron-Cohen, 2008, 1; NAS, 2011). Social communication difficulties can include problems with facial expressions and body language, or with conveying implicit meaning in written or spoken language (Baron-Cohen, 2008, 58). Many autistic people also experience the world differently from non-autistic people, in terms of their sensory and perceptual experiences of, for example, light levels or patterns, sounds, particular smells, colours, textures or tastes (Bogdashina, 2003, 44-83). This can affect the quality and/or intensity of what is experienced, resulting in hyper/hyposensitivities (i.e. a more or less intense experience of stimuli than the range typical in non-AS people), that tend to be multimodal (i.e. taking different experiential forms and occurring in different sense domains) and pervasive) (Kern et al., 2006; Klintwall et al., 2011; Leekam et al., 2007; Samson et al., 2011; Tomchek & Dunn, 2007).

How autism manifests can vary significantly between individuals and this is socially mediated, via a process of constant interaction with changing environments. For example, even within a setting where an annoying sound is present, a person may be able to persevere in their intended actions, if the social environment is conducive and/or their awareness is directed significantly away from the noise (Bogdashina, 2001, 4-7). However, if the social context and/or environment presents other issues, perhaps sensory (for example, too many sounds or lights) or social (for example, anxiety in the presence of unfamiliar company) then this can affect a person's threshold of tolerance (Bogdashina, 2001, 4-7). While problems with social and environmental aspects of the everyday world are common features of life for people on the spectrum, 'being autistic' should not be framed purely through a deficit model lens (Baron-Cohen et al., 2009; Gernsbacher et al., 2006; Milton, 2012). Indeed, there is evidence that autistics routinely outperform non-autistics in a range of perceptual, reasoning and comprehension tasks. However, these appear less likely to be reported, or are reported as further evidence of deficit rather than an associated strength (Dawson et al., 2007; Gernsbacher et al., 2006). Conversely, for many people, autistic experiences are central to their wellbeing and sense of self, and social and cultural constraints mediate the extent to which they can freely experience these ways of being (Gernsbacher et al., 2006; Milton & Moon, 2012a; Milton, 2012). This is not to argue that AS-related differences are reducible to either social or cultural factors; rather to emphasise that individual experiences of 'being AS' are inextricably linked to the conditions in which lives are lived (Molloy & Vasil, 2004).

Despite evidence in the autistic population of a range of neurodevelopmental differences when they are compared with non-autistics (Schroeder et al., 2010), autism remains a condition that is defined and diagnosed through observation. There exists no definitive account of its development, and current research points away from a single 'cause' towards a range of potential neurodevelopmental differences (Happe et al., 2006) - to say nothing of variations in social and cultural circumstances in which autistic people live. Hacking (1999) frames Autism in terms of an interface between biology and culture, where factors relating to each domain are necessary but not sufficient to explain or even define observed differences between autistic and non-autistic people. Further, he argues that, in autism, biological factors appear to interact with classifications through social processes, giving rise to what he terms an 'interactive' phenomenon (Hacking, 1999). Classifying an object as a table does not change anything about its material properties (Hacking refers to this as a 'flat effect' that is unchanging). However, classifying human beings can alter both the conceptual and

material conditions of what is observed, which can then, in turn, affect classifications, through what Hacking (1999) terms a 'looping effect'. For example, he observes that variations in institutional and interactive responses to those classified as 'autistic' can change the context in which features identified with autism may arise (Hacking, 1999). Setting up AS as a generalised deficit in sociality, for example, may frame social encounters with people categorised in such a way that breaches in interactions become more visible or more likely (e.g. in programs of therapy, support services, or changes to educational, study and workplace environments).

Exclusion and marginalisation of autistic voices – historical and contemporary examples.

Given these conditions, distributions of power and opportunities to speak in the process of knowledge production on autism matter very much in terms of how it is understood, and how autistic people are seen and treated by non-autistic others.

...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced (Williams, 1996, 14).

Talking about autism was, for many years after its emergence in the work of Leo Kanner (Feinstein, 2010; Grinker, 2008), the exclusive preserve of clinicians and researchers, where autistic people were objects of inspection, rather than active participants in the creation of knowledge relating to their own experiences. While the emergence of self-advocacy movements (for example: ASAN, 2013; Autscope, 2011) and also the entrance of autistic researchers into knowledge production in social research has begun to challenge these conditions (for example: Arnold, 2010; Graby, 2012; Milton, 2012; Murray et al., 2005), these tend to be the exception. The views and perspectives of autistic researchers are not homogenous, and it is not our intention to represent them as such. Rather, our point here is that inclusion of autistic people as equal participants can help to enrich the research process and guard against overly deterministic designs and interpretations.

Obtaining the views of disabled people is now a requirement of policy legislation, both nationally and internationally (Pellicano & Stears, 2011; U.N., 2006). Yet this remains tokenistic when policies and research concerning people with a particular disability fail to include them in a meaningful way in agenda setting in both research and service provision. Such a situation is reflected in the lack of involvement and representation that autistic people have in organisations with stated aims that include the support of autistic people (Milton et al., 2012). In particular, the experiences and needs of autistic adults are often poorly understood by service providers, and the experiences of adults are under-researched (Allard, 2009; Rosenblatt, 2008). Financial pressures may, of course, play a role in this, as Ne'eman observes:

Of over \$314 million in research funding, only 3% went to research into services, support and education and less than 1% went to research into the needs of adults (Ne'eman, 2011).

Consequently, research does not address the conflict between the groundswell of autistic voices and efforts of self-advocacy, on the one hand, and those espousing a discourse of deficiency and dependency on the other (Milton et al., 2012). Although many within the autistic community have adopted the political slogan of: 'Nothing about us, without us' (for example: ASAN, 2013), research in autism continues to silence autistic voices within knowledge production, also side-lining potential valuable insights from research that engages with lived experiences. Failure to acknowledge and explore the different personal

and social conditions in which autistic people live and implications for their wellbeing is therefore a significant barrier to impact in contemporary research.

The answer does not lie simply in funding research that engages with lived experience (although this is undoubtedly an important issue), but there is a need to explore how autistic people can be involved as participants in the processes of knowledge production. All too often, autistic participant contributions to social research are quarantined beneath what we refer to as a 'glass subheading', treated only as empirical material for inspection and analysis by non-autistic researchers, and thus opportunities for mutual reflection and exploration are missed. This is significant because it means that understandings of wellbeing - what makes life liveable and everyday worlds inhabitable for different autistic people - are framed by third-person observers. For example, Jennes-Coussens et al. (2006) explored the quality of life of 12 young AS men aged 18-21 through measures based upon the World Health Organisation's Quality of Life measure, with little discussion of how these factors might play out within the lives of specific participants. The authors claim at one point that 'results [relating to satisfaction with physical health] may relate to clumsiness of movements or to sensory hypersensitivity' (Jennes-Coussens et al., 2006, 410). However, they do not appear to have followed up on this point with participants in their semi-structured interviews, limiting the specificity and scope of this claim. In Lawrence et al.'s (2010) investigation of the transition to adulthood, the authors' use of Maslow's hierarchy of needs to frame important areas limits their engagement with first person narratives in their review of literature. While they emphasise 'self-actualisation' as important for maintaining quality of life, they give no examples of how this might be achieved by specific people, nor do they discuss what this might mean for different autistic people in different contexts. Elsewhere, Portway and Johnson (2005) explored the 'risks of a non-obvious disability' for adults diagnosed with Asperger Syndrome. Here the unqualified description of the behaviours of their participants as 'odd' or 'bizarre' means that they neglect to explore the potential meaning or significance of these activities as legitimate and valued experiences, or as important strategies for coping with social and/or sensory issues (2005, 80).

The failure to engage fully with first-person experiences in exploring the lives of autistic people is both ethically and epistemologically significant in the context of contemporary research, because wellbeing does not simply mean the absence of difficulty, but also the ability for individuals to be involved in their communities, and to pursue happiness, as underscored by the World Health Organisation's (WHO) definition of 'mental health':

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community (WHO, 2011).

In the case of autistic people, wellbeing also relates to a person's ability to experience ways of being that are compatible with their dispositions, without being forced to mimic non-autistic behaviours that can be confusing or bewildering to them (Bogdashina, 2001; Milton, 2012). It is known that autistic people - in particular adults - suffer high levels of social isolation, unemployment, and economic difficulties, as well as physical and mental ill health, and that this is attended by variable and often poor understanding of their needs (Allard, 2009; Rosenblatt, 2008). Therefore, it is crucial that researchers explore the subjective significance of AS related experiences in relation to wellbeing, as this may not be immediately apparent to non-AS observers.

Imposing narratives – ethical and epistemological consequences of dis/engagement with autistic authors.

Another worrying aspect of some academic publications that are positioned within or draw on theoretical and methodological resources from social science, is the imposition of narratives that produce a distorted picture of life experience - in part due to a failure to engage with the writings of autistic people. In their book *The Myth of Autism*, Timimi et al. (2010) argue that the changing history of the autism spectrum, and failure to provide clear etiological explanations indicates that the diagnostic label is of no scientific, clinical or social value, and should therefore be abolished. They claim that this would be a desirable outcome for those currently diagnosed as being on the spectrum - a bold step for which they provide worryingly little evidence or discussion in terms of concrete ethical implications (Bracher & Thackray, 2012). More troubling in the context of the present discussion, however, is the authors' failure to engage with a diversity of accounts of experience from autistic people themselves. This is problematic not only in epistemological terms, but also ethically. Much of the existing writing from autistic authors is critical of current diagnostic categories; something which casts further doubt on the ethical and intellectual integrity of many contemporary arguments.

Where autistic voices have been integrated into discussions by non-autistic academics, these tend to involve problematic interpretations of the source material, an example of which comes from Ruud Hendriks' (2012) *Autistic Company*. In this book, Hendriks explores how autistic and non-autistic people navigate a shared existence, and considers how one can talk about the unusual forms of interaction that take place (Hendriks, 2012). In so doing, the author approaches a topic not only of paramount importance within the field of autism studies, but also medical sociology more generally, in terms of how to build interactions and relationships with neurodiverse populations (Hendriks, 2012). His main focus is on the forms of living that autistic and non-autistic people establish together, and he suggests that the metaphors commonly used to describe autistic people underestimate commonalities; that dispositional differences are not irreconcilable extremes (Hendriks, 2012). Here, the reason for autistic people being outsiders in society is formulated as a lack of insight in context-related meaning. Hendriks concludes that a shared existence is dependent on the widening of companionship to include physical as well as mental connections (Hendriks, 2012).

However, Hendriks' selective engagement with the works of autistic authors leads to some highly questionable suggestions. For example, he suggests that a stimulus-free and controlling environment is the only way to help autistic people connect with others, and that 'leaving autistic people alone' will lead to them becoming lost in the world (Hendriks, 2012). This reifies behaviourist modification techniques to stimulate 'normal development' and reduce 'autistic behaviour' - techniques that are highly criticised by some autistic self-advocates (Milton & Moon, 2012b). While one would not recommend neglect for any child, building reciprocity requires mutuality of understanding rather than the one-sided imposition that Hendriks appears to advocate. As Ryan and Räisänen (2008) have observed, autistics are often very aware of the conditions of life 'over there' in the non-autistic world; and in a way that is not often reciprocated. Elsewhere, Ochs and Solomon (2010) have indicated that adjustments in dispositional alignments in parent/child interactions can help to alleviate some of the difficulties inherent in autistic/non-autistic interactions.

Hendriks asks how to prevent a non-autistic interpretation from 'gaining the upper hand after all' (Hendriks, 2012, 149). Co-researching and co-writing with an autistic writer or scholar

might provide a useful starting point. If interactional expertise is to be gained, it is essential that normative assumptions and impositions of non-autistic meanings are deconstructed. Instead, Hendriks' examination of autistic autobiographies ends up being an exercise in 'quote-mining' to fit the claims being made; claims that are often critiqued by some of the authors cited by Hendriks (such as Sinclair and Baggs) (Hendriks, 2012, 18-19, 149-150, 178). Despite seeking to position his research in the disability studies literature (Arnold, 2010; Goodley, 2011; Meekosha et al., 2013), Hendriks is not attuned to the anti-normative stance that characterises this body of work and end up working against the activist rallying cry of 'nothing about us, without us'. Indeed, if Hendriks' conceptualisations were valid, the social awareness required in order to enable collaboration between the autistic and non-autistic authors of the current paper could not have been achieved.

Possible alternatives

Despite the prevalence of exclusion in contemporary research, examples of good practice do exist, such as the *Autism Asperger Partnership in Research and Education (AASPIRE)* - a group that carries out research projects in collaboration with academic communities, 'relevant to the needs of adults on the spectrum' (Nicolaidis et al., 2011; Nicolaidis et al., 2012). This group advocates the use of 'community based participatory research' or 'participatory action research', where autistic people engage as equal partners throughout the research process (Nicolaidis et al., 2011; Nicolaidis et al., 2012). Some of the principles of this style of research are: to build on the strengths and resources of the community; to facilitate co-learning and 'capacity' building between participant; and to disseminate results to all partners. Parallel aspirations have been expressed by the autistic community in Britain: for example, the 'Autescape' conference in 2011 included a presentation concerning the 'owning' of autism research, providing advice with regard to how research is carried out and highlighting challenges to address when considering participation (Autescape, 2011; Kalen, 2011). More recently, an autistic run academic journal (Autonomy, 2013) has been established, and a project - entitled 'Theorising Autism' (Milton & Moon, 2012b) - has been set up with the aim of bringing autistic academics together, in order to bolster collaborative efforts.

Meanwhile the agenda of the majority of autism research continues to be dominated by concerns relating to finding a 'cause', normalisation through behavioural modification, and 'hopes of a cure', - wrapped in a rhetoric of 'scientifically supportable evidence-based practice' (Post et al. 2012). In order for there to be a significant shift in the research agenda, the silencing of autistic voices and tokenistic practices must be replaced by meaningful involvement of autistic people in understanding autism - including (but not limited to) the employment of appropriately trained autistic people in research teams. With such involvement, the research agenda would be broadened, rapport with research participants might improve, dissemination of findings would be less offensive to the autistic community, and autistic people would be less alienated from knowledge produced in the field. Crucially, such developments would increase the epistemological integrity of studies that seek to explore important questions relating to the wellbeing of autistic people.

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BSA Medical Sociology Study Group & Social Science and Medicine One-day Meeting

To celebrate Professor Dame Sally Macintyre's contribution to health inequalities research and policy

17 June, 2013, London School of Hygiene and Tropical Medicine, London

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Professor Dame Sally Macintyre's extraordinary contributions to the research field of health inequalities have had a huge impact across several disciplines and in relation to various social settings. The one-day event celebrated her major influence in medical sociology and policy in the UK and beyond for more than thirty years. As an early career researcher completing my doctoral thesis on bottom-up understandings of Patient and Public Involvement policies in England and Wales, I was new to the field of health inequalities. I certainly felt quite intimidated in attending such an important event as a novice and at times I found it challenging to follow some of the discussions. However, it was a great opportunity to develop my understanding of the subject and to meet other researchers interested in Professor Macintyre's work.

The day was very enlightening because the interactions of research and policy were discussed in historical perspective and I was particularly taken by reflections regarding the importance of the broader social context and everyday life in examining health inequalities. The event was divided into three main sessions in which several speakers examined their own studies and how Professor Macintyre's work (and her personal attributes) contributed to the field and to their personal development. Professor Hilary Graham from York University chaired the morning session dedicated to the research agenda for health inequalities that included reflections on the past and looking to the future.

Ana Diez Roux, Professor at the University of Michigan, reflected on how researchers approach the study of social determinants of health. She discussed an approach based on social class differences and how it developed into one that focused on life-course and the accumulation of risk through older age. This evolved further into a concern with multi-level determinants to health by exploring, for example, neighbourhood health effects and whether changes in environment affect health. The systems approach can be valuable in exploring social differences in health as they are shaped by the processes and dynamics of the system. Professor Roux's comments on the tension between methods and research questions were particularly interesting and she encouraged reflections on how they influence each other in practice.

Steve Cummins, Professor at the London School of Hygiene and Tropical Medicine, was the second speaker of the morning session. He emphasised the value of the notion of context as a framework for the study of health inequalities. Professor Macintyre herself had defined place as a 'black box' and argued for the need to explore the contextual meanings of the

concept and how those shape health inequalities. I realised that the importance of uncovering situated meanings is also a key feature of ethnography and as such it could be a suitable and particularly powerful approach to explore the topic in comparative perspective.

Professor Graham Hart from UCL concluded the session by discussing HIV and sexual health research. I was completely new to this area and I found his examination of how his research on gay men, HIV and AIDS affected the implementation of interventions and policy agendas revealing. As my research investigates participation policies in the NHS, I was particularly intrigued by Professor's Hart accounts of how he and his colleagues engaged with people in community settings in order to increase the number of people seeking HIV-testing by providing different opportunities. In doing so, the research team took account of context and place as factors that had to be built into strategies for tackling health inequalities in sexual health.

In the brief discussion session, the debate centred on the identified tension between methods and research, where researchers can be blinded by emphasising the selection of 'better methods'. Among the talking points was that researchers do need to ask the right questions as opposed to seeking better methods of investigation; also, one of the dangers is that the emphasis on publishing and obtaining funding may drive research, rather than the commitment to produce meaningful evidence.

The afternoon session brought together three speakers reflecting on the policy environment for health inequalities. They all emphasised the need to undertake effective evaluations of interventions tackling health inequalities, albeit in different areas of research. Professor Mark Petticrew, from the London School of Hygiene and Tropical Medicine, discussed the importance of considering complexity, arguing that as a result evaluations need to focus on the processes underlying interventions. It was fascinating to listen to his argument about the importance of identifying 'unintended unpredictable adverse effects' and potential 'hidden harms' of interventions. It is fundamental that the next generation of health inequalities studies build complexity into their research framework.

The second speaker, Professor Catherine Law from UCL, specifically addressed the topic of child health inequalities policies. She argued that though they supported rhetorically the idea of reducing inequalities, there was a failure to approach such policies in 'joined-up' ways. Professor Law emphasised the need to explore how certain interventions interact with the local contexts in which they are implemented, and mentioned the programme Sure Start as a practical example. It is fundamental to understand whether people in need actually access the programmes designed or whether, and why, some may be excluded from participation.

The last speaker of the session was Professor Karien Stronks from University of Amsterdam. In line with the other speakers, she supported the value of effective evaluations and the idea that complexity is a key theme in the study of health inequalities. Professor Stronks said it was crucial to improve understanding of the processes underlying policies in the making, and made the case for close collaboration between policy makers and a wide range of involved stakeholders. She also provided an intriguing reflection on the tension between the 'unjust' nature of health inequalities and the more socially accepted presence of income inequalities. Drawing on her first-hand experience of the Dutch context, Professor Stronks pointed at the tension between 'individual freedom' and the policies tackling health inequalities; she claimed that the latter are rhetorically relevant although actual policies privilege the former. She argued that we should not shy away from moral debates about the legitimacy of policies in relation to broader social values.

The last session of the event, 'Reflections', was a collection of brief personal memories

combined with professional considerations of Professor Macintyre's contribution to the study of health inequalities. I was interested to hear Dr Peter Craig, Chief Scientist Officer in Scotland, discussing how Professor's Macintyre work strongly encouraged us to examine multiple dimensions of inequalities and how the notion of place affected health. Dr Andrew Fraser from NHS Scotland discussed the importance of research evidence for policy makers. Lastly, Professor David Armstrong provided ironic reflections on 'the unintended consequences of Sally'. Professor Macintyre certainly contributed to raise the profile of medical sociology - 'from flaky to respectable' - and to convince the policy community that sociology is a key discipline in the field of medicine and health.

Professor Macintyre closed the event by emphasising the need to work collaboratively so as to influence policy meaningfully.

The meeting has been an excellent opportunity to listen to key speakers providing fascinating glimpses about the multidimensional nature of health inequalities by building on Professor Macintyre's outstanding work. As an early career researcher new to the subject, the discussions have been particularly useful to frame the topic through the identification of central issues: I have certainly been stimulated to develop in-depth knowledge of Professor Macintyre's ideas and to relate them to my current area of investigation. I believe that her exceptional contributions are fundamental for the next generation of researchers committed to explore - and to influence - the study of health inequalities.

Men's Experiences of Living with Parkinson's Disease

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ABSTRACT

The goal of this thesis is to explore men's experiences of living with Parkinson's Disease, a progressive neurological disorder predominantly affecting men in older age. Research into PD has been predominantly informed by a biomedical, neurological model. Although bringing significant benefit to PD's treatment, this approach fails to adequately consider the question of PD's lived experience, leading to major gaps in our knowledge of the condition and its effects on sufferer's lives. In addition, although making up the majority of sufferers, the specific needs of older men with PD have been neglected within wider research into PD. Using a phenomenological methodology concerned with men's experience of the lifeworld, and how this experience is influenced by gender and ageing, this study used narrative interviews combined with a photographic elicitation approach to ascertain the lived experiences of 15 men, from a number of different areas and of differing ages.

The findings of this thesis indicate that PD is more than simply a movement disorder. Instead it should be understood as a condition which disrupts the unity of the body, self and world. PD brings about particular challenges to men's experience of the lived body and lived time, distancing them from a shared experience of the lifeworld. Men also found ways to try and cope with their PD, but these approaches had to continually change as men moved through the illness. Finally, men's lived experience was intertwined with ageing and masculinity. PD posed a threat to men's masculine status; however men could also use masculinity as a resource to understand PD's various effects on their lives. How well men could respond to these changes had key implications for their continued well-being and quality of life, therefore giving insights into how future PD services can be improved.

This thesis concludes by making recommendations for the development of person and gender sensitive services in PD. These include paying greater attention to PD's lived experience and the stories men tell of their illness; engaging with the problems men identify that PD causes in their lives; and the greater provision of forms of information and psychosocial support which recognises all of PD's effects; including non-motor symptoms, psychosocial consequences and medication induced side effects.

Keywords: Parkinson's Disease; Embodiment; Phenomenology; Narrative; Masculinity; Ageing

Pharmacogenetics and the Pharmacy Profession: A Sociological Exploration

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ABSTRACT

Pharmacy, particularly in the community setting, has been subject to significant changes over the last three decades. Running concurrently to these changes has been the development of the field of pharmacogenetics, or 'personalised medicine', which is likely to have significant impacts on hospital and community pharmacy practice.

Despite this, little sociological research has been undertaken to map the contemporary pharmacy landscape into which pharmacogenetics may be integrated and the effects that pharmacogenetics may have on pharmacy.

Through 38 semi-structured interviews with diverse practitioners, this thesis addresses these gaps in the academic literature by positing a novel sociological model through which contemporary pharmacy practice may be analysed and examining the potential impacts of pharmacogenetics on it.

It is argued that a dual approach to the management of medicines intersects both community and hospital pharmacy. Within this dual medicines management model, codified, organisational interests in medicines management are practised alongside a more negotiated approach which is enacted through what has been called here the 'pharmacy gaze'. The pharmacy gaze characterises the ways in which medicines and the patient bodies to which they are administered are co-constructed by pharmacists through discourses of risk and toxicity.

Pharmacogenetics, it is argued, represents a way in which the pharmacy gaze, and patient bodies within it, may be increasingly molecularised and risk and toxicity increasingly managed at the genetic level within pharmacy practice. Within this, a number of 'pharmacogenetic futures' involving pharmacy testing, patient counselling and practitioner education are presented although these are argued to be highly speculative and to present a number of macro- and micro-level challenges for policy makers and pharmacists. The thesis concludes by making a number of recommendations as to how some of these challenges may be addressed.

Keywords: Pharmacogenetics, Pharmacy, Medicines, the Body

Formal employment, social capital and health-related quality of life: A cross-sectional analytical study among people living with HIV in Johannesburg, South Africa

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ABSTRACT

Ever since the seminal Marienthal studies during the Great Depression of the 1930s, studies have linked employment to health and well-being of individuals. However, employment participation for people living with HIV (PLHIV) may not necessarily provide positive health outcomes given negative social responses to HIV infection, particularly stigma and discrimination. Using causal steps approach, the study examines the extent to which the linkage between formal employment status and health-related quality of life is affected by both social capital and HIV-related stigma among PLHIV. Quantitative data were obtained from 554 male and female adults on HIV treatment for at least two years in South Africa. Health-related quality of life (HRQoL) was measured using the validated Medical Outcomes Short Form (SF-36) (Quality Metric, USA) and is represented by physical and mental component summary scores. Formally employed study participants experienced superior HRQoL in comparison to those not formally employed. Both employment status and physical and mental component summary scores were unrelated to objective measures of HIV disease status - CD4 count and viral load. Levels of social capital did not vary significantly by formal employment status. Perceived HIV-related stigma was significantly lower among formally employed study participants than those who were not formally employed, but only in the dimension of personalised stigma, after controlling for potential confounders. Social capital indicators were significantly positively associated with mental but were unrelated to physical component summary scores. All HIV-related stigma scale scores were inversely associated with social capital indicators and with physical and mental component summary scores, after controlling for potential confounders. These results provide little support for mediation of the relationship between formal employment status and HRQoL among PLHIV by social capital and HIV-related stigma. Both social capital and HIV-related stigma have independent relevance to, but formal employment accounts for the largest effect on the health and well-being of PLHIV.

Keywords: employment; social capital; HIV; Health-related quality of life; South Africa; Stigma

Girls/Women in Inverted Commas – Facing ‘Reality’ as an XY-Female

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ABSTRACT

XY-women with conditions such as Androgen Insensitivity Syndrome (AIS) have male sex chromosomes, internal (abdominal) testicular or gonadal streak tissue, and no ovaries or (usually) uterus, but are otherwise female in body form and gender identity/role. Many have no reason to doubt a female sex until they are investigated for failure to menstruate, yet clinicians have been known to enclose them in inverted commas in textbooks/papers.

Using mixed-method (quantitative and qualitative) empirical methodology, the study reveals how XY-women discovered their diagnosis, with an in-depth analysis of the medical and societal discourses that shaped the labels/identities to which they have been subjected or they have assumed. Data was collected by questionnaire from 114 women recruited via a peer support group. The study is interdisciplinary, spanning medicine, psychology, sociology and feminist gender theory. It is informed by a range of theories including patriarchy and medicalisation (including terminology issues), sexual dimorphism, sex versus gender, social construction, abjection, self-surveillance and performativity, and sexual difference and corporeality.

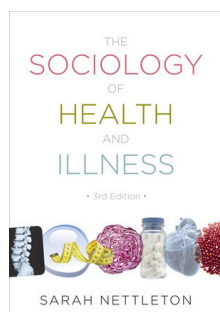
Many participants had experienced diagnostic secrecy by doctors, particularly in N. America. Younger participants had benefited from a recent move to truth disclosure. Participants had found the androcentric medical discourse/terminology difficult to reconcile with their female appearance, identity and social role; and did not approve of the degree of medicalisation. Infertility was the greatest personal concern but most thought that possession of a vagina was society's main criterion for womanhood. Most seemed secure in their female gender, although some were aware of a degree of performativity. Knowledge of their male biological attributes seemed problematic for many (especially those with Swyer Syndrome, but this needs clarifying using a larger sample), with expressions of inauthenticity, fraud or freakishness by some.

Participants showed little awareness of gender theory and even the idea of a sex versus gender conceptual split seemed confusing for many, but clearer to those in N. America. The majority seemed to construct a totally female sex, although some entertained the idea of an intersexed sex, particularly those in N. America and those with a lesbian or bisexual orientation. The lesbian/bisexual sub-group, and those with a PAIS diagnosis, also showed the greatest awareness of gender performativity.

Advocacy is a key aspect of the project, developing the argument that the androcentric focus of intersex medicine and the poor provision of clinical psychology restricts the opportunities for these patients to explore alternative discourses and non-medical meanings of their diagnosis; their 'reality' (with inverted commas) in post-modern terms.

Keywords: Intersex, XY-female, mixed-methods, feminist, gender, dimorphism, androcentrism, medicalisation, social construction, abjection, corporeality, Bio-medicalisation, Biographical disruption, Critical moments, Foucault, Genetic, Identity reconstruction, Male, Society, Stigma, Surveillance

Book ReviewBook Review



Nettleton, Sarah

The Sociology of Health and Illness (3rd Ed.)

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344pp

Reviewers: Tim Banks and Rebecca Dimond

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Sarah Nettleton's *The Sociology of Health and Illness* has become a classic textbook in medical sociology. This third edition is a welcome update, addressing the key topics that one would expect from a sociology text. Nettleton pays attention to the ever-changing relationships between health and illness in contemporary society. This covers tensions in the doctor/patient relationship; the diverse experience of illness and disability; and the role of patient organisations in influencing the policy agenda. In addition, the book has been brought up to date by reference to more recent research and, in recognition of the growing body of work around technology and innovation, now includes a new chapter focusing on emerging health technologies.

The first chapter provides an outline of the biomedical model and its challenges, with subsequent chapters focusing on a specific topic. A chapter on 'the social construction of medical knowledge' is followed by excellent accounts of 'lay health beliefs, lifestyle and risk', 'chronic illness and disability' and the 'sociology of the body'. After addressing 'lay professional interactions', 'social inequalities' and 'health care work', the remaining chapters look to the future in terms of 'UK health policy' and 'health technologies'.

This latest edition contains important updates to the last, published five years ago, reflecting the rapid changes in the field. The most significant alteration is the addition of the aforementioned chapter exploring the sociology of innovative health technology. This chapter highlights three technological advances, bio-economies, medical imaging and developments in genetic knowledge. Here Nettleton deftly draws on the contributions of prominent authors (including Webster, Law, Mol, Waldby, Rose, Hedgecoe, Mitchell and Hacking) in order to describe the implications of these developments and how they have been conceptualised.

Each chapter demonstrates Nettleton's depth and breadth of knowledge and her extensive research experience. In recognition of the changing nature of medicine, this book skilfully manages to combine recent accounts and theories with classic texts and the range of research drawn upon is particularly impressive. One of the most interesting features of this book is that Nettleton does not just refer to the work of other authors, but, on several occasions, includes excerpts from their original data. The inclusion of 'real world' examples, demonstrating the complexities of doctor-patient interactions, or the consequences of diagnosis, for example, is useful to allow readers to appreciate the practical application of theory. One minor criticism, however, is that, on occasion, reference to more recent empirical examples, rather than older and less well known research, might have been more persuasive.

While this book is highly appropriate for undergraduate social science students, it is also perfectly suited to postgraduate researchers who might need a solid starting point in order to investigate a particular line of enquiry. This text would also be attractive to medical students or health professionals new to sociology who require an overview of the field. By offering a comprehensive updated account, coupled with the fact it can be used at different levels of education, this is an essential book for inclusion on a medical sociology reading list. As a sociology text and reference, this book represents good value for money.

Although, as joint reviewers, we disagree about how easy it is to 'dip in' to this book (one of us felt the writing could be larger with more headings included) we both can report that, once you start reading, it is difficult to stop. This is a highly engaging book, drawing on useful examples and the writing is clear and accessible - which is certainly no mean feat, given the sometimes complex nature of the material and perspectives in which Nettleton is addressing. This book is successful in achieving the aim of providing a comprehensive in-depth account. It is accessible enough to offer concise summaries of key perspectives while, at the same time, providing sufficient depth for the reader to come away feeling they have a firm grasp of the main arguments.

Overall this book is to be highly recommended. It produces a rich and colourful account of medical sociology which will inspire those new to the field, as well as those who want to refresh their knowledge.

Book Review



A Public Health
Perspective on
End of Life Care
EDITED BY JOACHIM COHEN | LUC DELIENS

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In recent years discussion of both the social and clinical aspects of experiences of death and dying has found a more prominent place in a range of literature - academic, policy documents, autobiography and journalistic commentary in the press. The increase in writing about death, as both social and personal, can be seen as part of a wider discourse that positions death and dying as a public health issue. The argument that death is now managed by clinical professionals, with specialist skills and knowledge in end-of-life care, has been powerfully made by a number of commentators. For example, the ideas of Australian sociologist, Allan Kellehear, have been particularly influential in moving the debate about what might be termed a 'good death' from a mainly clinical/professional domain to a public health arena, wherein families and communities can 'reclaim' skills to enable them to care for their dying. It is this cultural shift that is at the core of this fascinating edited collection.

In drawing out some of the chapters for particular attention, I have in fact started from the end, so to speak. Allan Kellehear contributes the final chapter (before the editors' conclusion) in which he discusses how families in many contexts do want to care for their dying but, this is often characterised by high levels of stress, limited practical information and, in some cultures, by stigma and taboo. The chapter highlights that end-of-life care in families and within communities is experienced as complex, contingent and uncertain.

The book is organised into five main parts - clinical and social context of death and dying; end-of-life care: provision, access and characteristics; end-of-life care settings; inequalities at the end of life: under-served groups; end-of-life care policies. Each part has a number of chapters that focus specifically on discrete aspects of the part's overall theme and this is useful for the reader. Terms, context and some key literature are identified to give each chapter both theoretical and empirical boundaries.

The chapters that I found most useful appear in the parts on End-of-life-care: Provision, Access and Characteristics and the part on Care Settings. Linda Emanuel's chapter (8) on communication between patient and caregiver discusses how communication is central to shared decision-making that is culturally appropriate and person-centred. She highlights the concepts of 'creative adaptation' and 'integration' as holistic techniques to support the wishes of the dying person. Where, for example, verbal communication is impeded by end stage disease, adapting to written forms can enable the dying person to retain an acceptable state of mind. 'Integration' is akin to life review that entails bringing one's personal story to closure. Elsewhere (see Watts, 2009) I have argued that life review is contested with potentially

negative as well as positive outcomes for the dying person. This dualism is not referred to by Emanuel. However, her claim that 'integration involves vesting parts of the dying person in the surviving people', in terms of 'wisdom's', values, role transfers and memorabilia, extends thinking in this area.

Because most people in the West continue to die in acute hospitals, I was particularly interested in the ideas of Kelley and her colleagues (chapter 11) about approaches to the delivery of palliative care in this setting. The data in the chapter about the overall growth of palliative care services in hospitals illustrates that this is not evenly spread and that this is particularly limited in many countries in Africa, South-East Asia and Eastern Europe. This returns us to the precept promoted by the World Health Organisation that access to quality end-of-life care is a basic human right. It seems that the setting of death continues to be a key determinant in achieving this.

Overall, this is a very accessible text that draws out current thinking on this important topic. Its international focus on diverse approaches that promote a 'good enough death' takes into account the burgeoning global population, the AIDS crisis in sub-Saharan Africa and the problem in the west of so many people 'living too long'. A useful and focused book, the introductory and closing chapters written by the editors skilfully draw out key ideas and challenges and I would suggest reading both of these first before embarking on the other chapters. Because of its multiple perspectives, this book will be helpful reading for clinicians, academics, students and policy-makers concerned with 'how people die' in the context of both the developed and the developing world.

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Current Online First Articles: A Digest

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This digest provides a personal selection of articles shortly to be published in a range of relevant journals relevant to medical sociology. The articles are drawn from 'Articles in Press' on the Social Science and Medicine (SSM) website; 'Early View' on the Sociology of Health & Illness (SHI) website and 'Online First' on the Health website. The wide range of articles available makes the selection for review a challenging and complex activity; is it best to focus on a few themes or include a diverse range of topics or methodological studies? I concluded it was more effective to focus on themes. Thus the themes underpinning my choices were food and alcohol for no other reason than I was struck by the number of articles related to consumption of both. From a possible 23 articles for inclusion, 11 were related to the consumption of alcohol or food.

I start with an article from SSM reporting on an interesting study funded by the Joseph Rowntree Foundation. Townshend's (2013) article '**Youth, alcohol and place-based leisure behaviours: A study of two locations in England**' draws on an 18 month qualitative study that focused on the lives and drinking behaviours of 'ordinary' 15 and 16 year olds (n=125). While the author, points out that the majority of young people do not regularly drink excessively, heavy sessional drinking or 'binge' drinking is associated with negative health and social consequences for those who do. The author found that most participants in both locations had first tried a small amount of alcohol from the age of 11-13 usually at a special family occasion such as Christmas, a wedding, or a relative's birthday. Attempts made by parents to control their alcohol consumption often failed and as young people grew up, the family centred nature of alcohol consumption quickly changed to one that was focused on friendships and socialisation and having fun. Adults seemed to be complicit in this pattern of consumption and didn't have serious health concerns; being more concerned about young people being sick or vomiting at parties than their health.

Another article from SSM '**The spatial and temporal development of binge drinking in England 2001-2009**' by Twigg and Moon (2013) uses secondary analysis of the Health Survey for England, to make observations about the development of binge drinking. Defined as brief periods of heavy drinking (one day or evening) within a longer period of several weeks of lower consumption or even abstinence, binge drinking has been associated with acute and chronic health problems and premature mortality. The authors found that single people are more likely to binge drink than married or co-habiting couples; non-white ethnicity decreases the risk of binge drinking; students are at less risk of binge drinking. Young men are more likely to binge drink than older men and women are less likely to binge but are more likely to concentrate their high intake on a single day. The study shows that there are marked regional variations in binge drinking with levels in North East England much higher than those in London and the South. In general, binge drinking is higher for those living in urban areas compared to suburban or rural areas. The authors suggest that there is something about living in the north of England that increases the likelihood of binge drinking that is not easily explained by the characteristics of respondents.

A third article from SSM addresses alcohol consumption but focuses on the American

experience. In **'Associations of Occupational Attributes and Excessive Drinking'**, Barnes et al (2013) use a quantitative approach to conduct a secondary analysis of two large data sets to determine whether occupation attributes were associated with alcohol use. Using a representative sample of 6,426 workers aged 41-49 years, the authors found that physical demands, job autonomy, and levels of social engagement explained variations in consumption. Men working in physical demanding occupations drank more frequently and consumed more yet women in similar jobs did not. This remained true irrespective of socio-economic variables that were factored in. Low levels of job autonomy were not associated with higher levels of drinking. Men and women, working in more socially engaging occupations such as health care practitioners, drank less frequently. The authors suggest that male workers in physically demanding occupations could be suitable targets for employee-assistance programmes to prevent alcohol misuse.

In Health there is an article entitled **'Men give in to chips and beer too easily': How working-class men make sense of gender differences in health'**. I selected the article on the basis that it too would focus on the concept of alcohol or food but instead Dolan (2013) provides evidence that the construction and enactment of hegemonic masculine identities may come at a considerable cost to men's health. Dolan's study explores how white heterosexual males (N=22) from two working class areas in England, make sense of class and its impact on health. He found that regardless of their socio-economic position, men's responses concentrated on perceived gender differences in attitude towards health and health-related behaviours, such as smoking, drinking and poor diet. Study participants did not consider the enactment of working-class masculinity to be health-enhancing. They believed that factors associated with working-class employment, individual behaviour and psychosocial environment, impacted upon men differently compared to women. Many also believed the stresses associated with unemployment had a greater intensity and were potentially more harmful to men than women. Distinctions were made based upon biological and evolutionary characteristics, exemplified by aggression and courage, were driven by powerful male hormones, which 'hardwired' certain attributes into men's brains and bodies. Women, in contrast, were programmed for social interaction and predisposed to pay more attention to the well-being of others. These characterisations were used to explain why potentially health-damaging beliefs and behaviours were far more prevalent among men than women. Thus, while men were not entirely blameless, respondents felt that men should not be held entirely responsible for their poorer health. Dolan (2013) concludes that men may engage in damaging practices in order to achieve and stabilise their dominance over women, as well as other groups of men and that because of broader structural influences on men's health, further research in this area needs to include the field of political economy.

Another paper that looks at the relationship between food and health is featured on the SSM website. This is by Carroll-Scott et al. (2013) and is entitled **'Disentangling neighborhood contextual associations with child body mass index, diet, and physical activity: The role of built, socioeconomic, and social environments'**. This reports on a large chronic disease prevention study conducted by the Yale School of Public Health carried out in the USA. Focusing on pre-adolescent children living in New Haven, Connecticut, the study examined associations between built, socioeconomic and social characteristics of a child's residential environment on body mass index, diet, and physical activity. The authors found that unhealthy behaviours were associated with built environment inhibitors such as easy access to fast food outlets; students living within a 5 minute walk of a fast food outlet had a higher BMI and ate more unhealthy food. Healthy behaviours were linked with built, social, and socioeconomic environment assets such as easy access to parks, social ties and affluence; students with easy access to parks, playgrounds, and gyms were associated with

more frequent healthy eating and exercise and a lower BMI. Students living in more affluent neighbourhoods also reported more frequent healthy eating. The authors conclude that interventions to prevent childhood obesity need to focus on local environments rather than individual factors.

The final paper, ***'Precursors to Overnutrition: The Effects of Household Market Food Expenditures on Measures of Body Composition Among Tsimane'***, continues to address the topic of food and obesity, but focuses on the Bolivian experience. In this paper Rosinger et al (2013) addresses the relationship between household expenditure on "market" foods and body composition among the Tsimane', a forager-horticulturalist indigenous group in the Bolivian Amazon, who are in the early stages of a nutritional transition. Drawing on data from a survey of adults (n=1129) aged over 16 years, from 563 households in 40 Tsimane villages, the study found that the majority of respondents were overweight rather than obese; that men living in more affluent households had significantly higher BMI than men in households where market foods were not bought or consumed; having the resources to purchase foods such as noodles, deep fried foods and soft drinks from a market, was associated with higher BMIs. The authors suggest that household spending on market foods may be precursors to overnutrition among rural men. For the Tsimane, a population living with high prevalence of infectious diseases, market foods provide additional sources of fat and calories that may buffer against nutritional deficiencies in the short-term, but may lead to chronic diseases in the long-term. This is a lesson that the developed western economies know only too well.

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