Researching suffering, subjugated knowledge and practices of health:

An interview with Rita Giacaman

The work of Rita Giacaman and the Institute of Community and Public Health, Birzeit University

Rita Giacaman is Professor of Public Health at the Institute of Community and Public Health at Birzeit University in the West Bank, Palestine. During the 1980s, she participated as a researcher and practitioner in the Palestinian social action movement, which led to the development of the Palestinian primary health care model. During the 1990s, Rita participated in building the Palestinian community based disability rehabilitation network. Since 2000, she has been focusing on understanding the impact of chronic war-like conditions and excessive exposure to violence on the health and wellbeing of Palestinians, with an emphasis on psychosocial health, and ways in which interventions could generate the needed active and positive resilience and resistance to ongoing war-like conditions, especially among youth. Rita Giacaman can be contacted by email: rita@birzeit.edu.

Abstract

The work of the Institute of Community and Public Health at Birzeit University, Palestine, seeks to link the biological/biomedical sphere to the political sphere through the concept of suffering. This interview explores the ways they work to expose the sociopolitical conditions of life in order to simultaneously personalise war and politicise health.

Key words: health research, suffering, Palestine, resistance, subjugated knowledge

David: Since we last spoke about the ways in which you and your team have been 'Researching health, justice and the capacity to endure' (Giacaman, 2014), you have been further researching subjugated Palestinian knowledges about suffering and about endurance particularly as these relate to health. One aspect of your work involves the importance of honouring local idioms and local constructs. Can you say more about this?

Rita: Our work at the Institute of Community and Public Health at Birzeit University seeks to link the biological/biomedical sphere to the political sphere through the concept of suffering. We seek to expose the sociopolitical conditions of life in order to simultaneously personalise war and politicise health. To do this, we have had to develop a conceptual framework (Giacaman, 2018) that rests on several notions which are not Western and are locally relevant.

Conceptualisations of health in the West are primarily individualised, but in our research we don't think of individuals, we think of persons, and we think of persons because persons are raised here with rights and responsibilities towards the collective. When we speak of the health of persons, this includes the health of those with whom they are connected. We consider health beyond the individual and also beyond the immediate nuclear family. Matters of health here in Palestine concern the extended family and beyond. These considerations raise questions as to the relevance and adaptability of individualised conceptions of health in the West to our context.

This has implications beyond research because once you see person (and their responsibilities towards the collective), then you begin to realise that what you need to do as health practitioners may not necessarily be an individual therapy/treatment. Instead of therapy/treatment with the individual, which goes hand-in-hand with a biomedical model, we talk about *practices* of health. We go beyond the biomedical, because the problem here with trauma and suffering is not 'between the ears', as Derek Summerfield notes (Summerfield, 2005), it involves social political causes, and social political causes require social political resolution.

In talking about 'practices of health', these can be interventions by professionals but practices can also include what people do to help themselves and each other. Quite often, what we have here is that people heal by going back to normal as quickly as possible, by re-joining collective activities, and by talking about their experiences with family and friends. Our experience indicates that people here tend to prefer talking with friends and family instead of wanting to seek professional help following traumatic experiences.

Our framework is not based on a dichotomy, either sick or not sick; either disease or not disease. Instead we view health as a continuum between ease and disease which can alter day-by-day. Depending on the balance between everyday exposure to violence including humiliations and resources – for example family support, social support, financial support – health status oscillates back and forth and never in a straight line.

The conventional Western biomedical model emphasises biological factors and gives little consideration to social, environmental, psychological or political factors. But we do not see these as separate. Depending on the severity and chronicity of humiliations and violations, these can lead to disease. In the past, when I was a student in the United States, I used to speak about how my grandmother would say to me, 'Don't upset your father lest he gets hypertension or diabetes'. The conventional Western biomedical model used to laugh at such folk knowledge but now we know from scientific literature (Cohen, Janicki-Deverts & Miller, 2007) that stress through distress can lead to disease and not only diabetes or hypertension, but also cancer and other chronic health conditions.

Because we conceptualise health on an ease-disease continuum, the idioms that people use to denote their health or unhealthy states, their stress or distress, are very significant. Understanding where someone's experiences lie on the continuum is key to helping alleviate some of that suffering. There may be no disease recorded or diagnosed but they don't feel good. We refer to this as having 'invisible wounds' – invisible wounds which, if not paid attention to can turn to disease over the life course. In order to pay attention to these experiences, these 'invisible wounds', they need to be named, and this is where particular, local, personal idioms are significant. This seems to fit well with narrative practice.

DD: Yes, I think your determination to honour local idioms and to assist people to find their own language to describe what have previously been 'invisible wounds'

or un-named hardships, fits very closely with the narrative practice of using 'experience-near language' and paying close attention to the politics of naming. I recall some of Michael White's questions about the politics of naming and diagnosis. While he was speaking about realms of mental health diagnosis, I think these considerations of naming and validating local idioms are relevant in many contexts:

> *What knowledges are privileged in a particular process of naming, and what knowledges are rendered irrelevant or are disqualified in this process? Who is qualified to speak and to name, and under what circumstances is it acceptable for them to do so? What relational practices and techniques of power are associated with acts of naming, of diagnosing, and what are the real effects, on people's lives, of these practices and techniques?* (White, 1995, p. 119).

On a related note, I am extremely interested in your determination to find ways of researching and honouring the real effects of human insecurity and humiliation, both personal and collective …

RG: Yes, we are determined to find forms of research that meaningfully investigate the effects of different forms of suffering on people's health outcomes. How else can we convey the real effects of Israeli military occupation occupation and human rights violations? We have therefore developed individual scales in relation to 'human insecurity' and 'humiliation' and we're now working on further domains. For example, the notion of deprivation.

While deprivation is taken seriously in the field of economics, the focus is usually only on the material/financial. Through a study in the Gaza strip (Giacaman & Ghandour, 2016) people described to us how deprivation certainly includes being physically/materially deprived through lack of money, but other forms of deprivation have also been articulated. For example, deprivation because people are unable to have an education that they want. Or deprivation because people are not able to cross from the Gaza strip to the West Bank. Or deprivation because they are denied the right to travel to get treatment. They have also articulated realms of political deprivation, related to the split between Fatah and Hamas. And some people have spoken of forms of deprivation because the society has become much more conservative since the first intifada.

These are diverse forms of deprivation, not only financial. This seems a key issue when researching social suffering because either we are stuck with the biomedical model or we are stuck with the economic model and, while wishing to give all due respect for these two models, they need to be put in their place. For too long, people's suffering has been understood through the discourses of the biomedical or the economic.

As well as trying to create a measure in relation to deprivation, we are also interested in the domain of uncertainty. People here live in such terrible uncertainty. When I looked at the literature, I was surprised because it seems that uncertainty has mostly been conceptualised by US psychologists, and is often described in ways akin to an individual characteristic. For example, I've seen scales that refer to things like, 'I can't stand being taken by surprise' or 'Uncertainty stops me from having a firm opinion'. This way of looking at uncertainty surprised me, because the sorts of uncertainties we are interested in researching are the effects of not being sure if I can get out of the house and get to work; not being sure I can come back from work and find my children safe; not being sure I can get my children to school safely; not being sure I can travel to visit my family in the north; not being sure if my land will not be confiscated. We want to understand the effects of such uncertainty on people's health outcomes. This is something completely different than researching uncertainty as if it is some kind of individual characteristic.

We have also linked up with an academic specialist in law and a lawyer who is on the faculty at Birzeit University, because part of the domain of social suffering relates to violations of human rights, so we want to try to create some measures that might be able to assist us to track the health consequences of human rights violations. Overtime, we might then be able to conduct comparative research. Perhaps some Aboriginal Australian colleagues might be interested in being involved?

DD: We will certainly share this interview with First Nations colleagues and put them in touch with you. One current Aboriginal participant in the Master of Narrative Therapy and Community Work, Rebecca Smith, inspired by your development of specific measures relevant to the Palestinian context, is now interested in developing a way of researching the effects of racism (including fear) on the lives of Indigenous women and men currently incarcerated.

Your determination to use health research to articulate and honour the effects of human rights violations, reminds me also of the work you have conducted with Yoke Rabaia and others in relation to wellbeing and pressures of daily life (Rabaia, de Jong, Abdullah, Giacaman & van de Ven, 2018). There are a number of aspects of that research that seem really relevant to an Australian context, whereby you are seeking to honour day-to-day contextual injustices or stressors, and the way you call for including politics and history in health research. Can you say anything more about that research?

RG: The research you mention took place in the north of the West Bank, examining the everyday stresses and pressures of life in two different Palestinian villages and exploring their effects on health. In contemporary Palestine, our everyday lives and our health are powerfully affected by the broader political situation, by Israeli military occupation, and the lack of political freedoms. We each do what we can to try to influence this broader political predicant in different ways. We use what agency we have, including through academia, through building institutions, through publishing, and so on. And yet the political predicaments and injustices continue.

And so, while we continue to do what we can about the bigger political predicaments, we also wish to articulate, research, report and hopefully influence the pressures and stressors of daily life experienced by children, young people, adults and the elderly in Palestinian villages, refugee camps and cities. These pressures include things like not having enough money, not being able to go out, physical and mental health and violence in the family. These are daily realms of suffering and distress and there may be things that can be done to ameliorate some of them. That's the hope and beauty of this line of research. We are trying to investigate the daily stressors and pressures that we can alert policy makers to, and that we can seek to influence, while we continue to give voice to the effects of broader occupation.

DD: That research also describes how political pressure is associated with backaches in one village, but not in the other. I am interested in this embodied expression of distress, or embodied expression of resistance, and how it might vary in particular circumstances, or be given different meanings. Narrative practitioners in Rwanda are currently exploring these realms. Can you tell me more about your work in Palestine about this?

RG: Yes, of course. In this study there were two villages, in one, people were living a more traditional life, far away from the confiscation of land. In the other village, not only are lands being confiscated, but the building of the separation wall by Israeli forces has severed them from their land and also severed them from work outside their village. This sudden severing is a political issue, as are the daily checkpoints and other forces of occupation that they live with, and these turn into health symptoms. From this study and others (Giacaman, Shannon, Saaab, Arya & Boyce, 2007; Giacaman, Abu-Rmeileh, Husseini, Saab, & Boyce, 2007), we have noticed that the political oppression experienced by Palestinians often turns into somatic symptoms – especially backache, stomachache, headache, all sorts of aches. Difficulty breathing and a quickened heartbeat are other somatic or embodied expressions. We have developed a scale to make visible these somatic/ emotional symptoms, but of course these vary across cultures, countries and political contexts. And in this study we were examining the relationships between somatic experiences and particular forms of daily political, social and financial pressures.

DD: It seems really significant how your research is seeking to make links between these embodied expressions and political pressures. I suspect racism, sexism, dispossession and other forms of oppression lead to particular embodied experiences in Australia too but I don't know of any health research that is trying to make this visible in the ways in which your team is doing.

There is one other research project that I want to ask you about. This was exploring the experience of children whose fathers are in detention (Rabaia, Kassis, Amro, Giacaman, & Reis, 2018). There are a couple of themes within this work that seem very significant. Firstly, this seems to me to be what I would refer to as 'double-storied' research (Denborough, 2006; Marlowe, 2003) – it honours and articulates what people are enduring *and* it honours and articulates their resistance or how they were coping. Could you say more about this?

RG: The children in this study had experienced significant traumatic events in relation to the imprisonment of their fathers, not only the actual arrest – how the Israeli military came into their homes at midnight – that's typical, but also the ongoing absence of their father, the difficulty of visiting him, and the sudden control of the children and the wife by the in-laws.

Within our framework, we want to make visible the political, the domestic and the communal. Until recently, we have not looked carefully enough at communal violence. What we have discovered from research with these children and their mothers is that there's substantial communal violence against children and mothers when fathers are political prisoners. This is in contrast to the 1980s, during the heyday of the first uprising/intifada, where social support and social solidarity were paramount. These days it seems that this solidarity has not vanished altogether, but it has diminished considerably.

With the children of the prisoners, what we found is that they tend to be isolated from other children. Families of other children stay away from them, because it's a political imprisonment and they don't 'want any trouble'. The other point which is very important is that the in-laws, the grandparents, and especially the husband's brothers, often begin to control the children. These uncles become responsible for them in the absence of the father, and they don't necessarily treat them well, although of course there are exceptions. The exceptions are often the uncles on the mother's side. It can become so bad with the father's side that they seek out the uncles on the mother's side for recourse.

We found something similar with the women. The minute the husband is imprisoned, the woman is then expected not to get out of the house, to wear black, not to live her normal life, not to wear make-up, not to go to the gym. We were told some quite shocking stories. The communal violence/pressures can make it an impossibility for the woman to stay where she is living so that she picks up her children and goes to live in her parents' house, where they are comforted much better. Of course this cannot be generalised and is not possible for all women, but there's a pattern nevertheless.

In these situations, while the husband is politically imprisoned, there is a triple captivity for the women and also for the children. There's the captivity of the father which they are having to deal with. There's the captivity of living under occupation (having to cross checkpoints, get permits, wait for a whole day without having to go to the bathroom, in buses, and so on), and then there's the captivity of the community. It's a triple captivity (Giacaman & Johnson, 2013).

We also researched how children cope with their sadness and this predicament. There were two very interesting findings. One involved the children responding strongly whenever anyone would say 'we understand'. They would say, 'oh no, you don't understand. No-one will understand until they have been through that experience.' And they called for groups of children who have had the same experience to be brought together for exchanges, to share experiences, to engage in narrative practice together.

What was also very significant was that once children become adolescents, they begin to become carers, they give back. Children are not only receivers of support but also extend support to their mothers, siblings, and even their father in prison. These acts of agency, this capacity not only to endure, but also to resist by helping others in the family, gives them a lot of strength and pride. They honour themselves by doing something, and they earn the respect of others by doing so. And yet, in most research, this agency of children is obscured.

DD: It seems very significant that this research, in making visible children's agency and their requests, provides some clear direction for practitioners. The children and young people are requesting opportunities to meet with others with similar experiences to exchange knowledge as they know that is what will generate understanding. And secondly, that the work or practitioners also involves making visible, recognising and honouring, the skills, actions and agency of young people. That one of the tasks of practitioners involves creating forums for acknowledgement and recognition of children and young people's acts of care for others. This is a very different way of understanding how the wider world can respond. Not only is support and connection important, but *recognition* of children's agency, children's actions, is also significant. This is certainly very relevant to narrative practitioners (White, 2006; Yuen, 2007). Thanks so much for this conversation Rita.

I will look forward to the next one!

RG: It's great to talk about this. Let us think more and together …

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