



Researching health, justice and the capacity to endure

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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, occupied Palestinian territory. 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 rita@birzeit.edu.

This interview took place at Berzeit University in Ramallah, Palestine, in May 2014. Interviewers were David Denborough, Cheryl White and Marnie Sather.

In this interview, Rita Giacaman, outlines an alternative approach to mental health research that relates to Foucault's (1976) call for an 'insurrection of subjugated knowledges' (p.81). Building on Palestinian experiences of social suffering, and honouring local idioms, the work of the Institute of Community and Public Health at Birzeit University, refuses to separate health from justice.

Keywords: health research, humiliation, capacity to endure, Palestine.

Would it be appropriate to start by outlining the history of your efforts to develop health research that is meaningful in a Palestinian context?

Here in Palestine, our research is trying, and succeeding to some extent, to undo the dominance of Western knowledge on people from the 'developing world'. Our journey with research, and our questioning of the frameworks presented in the West, came in the early 1980s. Living under Israeli military occupation, the conditions were so glaring that in 1981 we began to realise and describe the ways in which health is a social construction. At this time, mainstream health research was overwhelmingly focused on the biomedical. And yet, we began to see very clearly that if we really wanted to improve health outcomes, we would need to do something outside the clinic. We would need to create research that could assist in transforming the daily life and the living conditions of our people. It was because of the Israeli military occupation of Palestinian land that our conceptions of health research had to change.

From that time on, we've been on a journey that has involved reading the international literature, arguing with it and asking 'why are they presenting health that way?' Often we would realise that rather than researching health, the field was only researching disease. For instance, when exploring diabetes, the research would focus on hypertension, not any broader social factors. Even when it came to studying Palestinians' exposure to violence, researchers would focus only on the physical aspects of exposure to Israeli political violence and they would start counting, counting, counting, the dead, the injured, and the disabled.

At one point we began to say, well the dead are 100 percent dead, what do we do with the living? What research would be relevant to improving the lives of the living? Secondly, we began to say, rather than researching only disease, let's look at health. We know that health and disease are a continuum. People oscillate between health and disease (or ease-disease) every day depending on the insults that we are subjected to. These insults could be a physical, material, psychological. Every day, we oscillate back and forth, back and forth on this continuum of health/disease. If the insults are repetitive then we move to the disease end of the spectrum. This is true for mental health but it's also relevant for physical health. Why? We know now from the international literature that stress can lead to disease. And thirdly, we began to ask, why is it that Palestinians are presented in a particular way in the literature, either as victims, terrorists or as refugees but in each case without a 'psychology', without any descriptions of agency or purpose, without any recognition that the circumstance of Palestinians affects our inner experience, mental health as well as physical.

The ways in which Palestinians from 1948 were described in health research seemed to be written with the assumption that we were subhuman. Until in 1986, a wonderful person, an academic and psychologist called Rajja-Leena Punamaki came here and began to document that Palestinians were actually traumatised inside, there were wounds inside, not only on our bodies. This development led to two contradictory outcomes. On one hand, this research cemented the idea that we can be traumatised and we are therefore human, and as such we joined the human community because we have a psychology. And on the other hand, Palestinians clutched to this new trauma discourse to such an extent that this allowed the trauma industry to come in and to begin dumping on us inappropriate one-to-one therapies

and medications which threatened to exclude the Palestinian call for justice (a la Foucault). Rather than suffering from injustice and the remedy being justice, now we were suffering from trauma and the remedy might be therapy or medication!

It's very fraught isn't it, this renewed form of psychological colonisation ...

This was the contradiction. On the one hand it was good, on the other hand it was problematic. We then began to see a new form of health research that would promote result such as '96 percent of Palestinian Gaza kids have PTSD'. Such research implies that 96 percent of kids in Gaza are mad, suffering from a psychological malady. Now it was time for us to say 'Hey wait a minute, that's not how we see ourselves. Wait a minute, why are you writing about us, we should write about ourselves.'

The journey continued by us asking the question, 'What is the problem with the Western discourse on Palestinian health?' We gradually began to realise that a major problem often resided within its framing conceptualisation. Researchers were generally asking the wrong kind of question. For example, we saw international aid coming in asking the question, 'How can we get these 'violent' Palestinian youth off the streets?'. We would question the assumption in that question that implies that Palestinian youth are diabolic by definition and by genetics, and we would seek to ask a quite different question: 'Why are Palestinian youth exhibiting violent behaviour?' Asking this question, would unearth the violations that these young people have experienced, as well as their hopes for change, for justice.

Gradually we began to say that some of the research frameworks, methodologies and metrics available from the West are problematic. Mind you, we're not throwing the baby out with the bathwater. But when you try a western developed questionnaire on distress here in Palestine, it just doesn't jive! This has meant we have needed to develop our own methods and concepts. Within mental health, culture is of the essence. There is no universality for the expression of distress. This is now known and more widely acknowledged, but this was less true in the mid-1990s. Now it is known. Even the people from the International Classification of Disease (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) are beginning to recognise that their diagnostic categories are highly Western biased. In fact they came to the Middle East to discuss this recently. They're beginning to see that manifestations of distress or wellbeing for that matter, can vary vividly across different cultures.

Can you say more about your work to develop an alternative approach to mental health research?

The main problem with Western mental health diagnostic instruments is very simple. The large majority depend on measuring 'symptoms' linked to particular Western diagnoses of distress. Our research does not rely exclusively on medical symptoms, but instead links mental health to indicators of social well-being and quality of life. Our approach places social suffering within an ease-disease continuum. Depending on context, the majority of Palestinians, who live in severe distress as they endure the suffering and trauma of chronic warlike conditions, are seen as oscillating in the grey areas between ease and disease.

To adequately research and/or describe these experiences requires using local language, rather than clinical and technical

language which fails to capture the range and nuances of experience related to an array of ill-health states. Our research (Giacaman 2010) reveals that as Palestinians on the West Bank oscillate back and forth on an ease-disease continuum, local expressions and idioms describe a holistic state of health, encompassing both the physical and the mental. These expressions include: something is wrong with him (malo ishi); wilted (dablan); not happy (mish mabsut); not able (mish qader); low energy (habet); no energy to complete daily activities (ma fish mrueh); down (kayes); tired (ta'ban); broken or achy (mkasswar); ill (ayyan); and finally, sick (marid). These expressions convey varying degrees of compromised well-being, with the last, marid, formalised as an ill-health condition usually endorsed by a doctor's visit and/or prescription.

As I understand it, as well as honouring local idioms and using these as openings to understanding and honouring local Palestinian social suffering, you have also developed new research instruments?

Yes we have needed to develop new instruments. Before I discuss these, and how we have developed them, it's relevant to note that where appropriate we still use more generalised measures. For instance, along the way, we discovered that the WHO5 Wellbeing Index, which seeks to measure 'quality of life', has been an excellent research instrument here. We tested this WHO5 Wellbeing Index here in Palestine (including testing for internal consistency) and used factor analysis. Factor analysis is interesting but it only makes sense when you know the culture in which you are operating. We apply such an analysis with cultural judgement because we know our society. Through combining factor analysis with a knowledge of our society, we've found that the WHO5 Wellbeing Index works very well. One of the reasons for this, we think, is that it is seeking to measure wellbeing/quality of life, rather than measuring symptoms. It is measuring health, not disease or disorder. It is a useful measurement of health, because if we find it is constantly deteriorating then we believe that this ought to be a cause for worry. A deterioration in health/wellbeing increases the likelihood of disease.

Can you say more about the measures that you have specifically developed for the Palestinian context?

We have developed specific measures which are relevant to Palestinians, and maybe to others. For example, the United Nations Development Program (UNDP) keeps talking about 'human insecurity' which is an excellent concept. Here in Palestine, qualitative surveys we have conducted have indicated that fear of attack, and fear for the safety of one's family, pervade Palestinians' experience. We are ruled not only with brute force, we are ruled with ambiguity, uncertainty and human insecurity. Because this concept is relevant to our situation, we decided to actually try to measure 'human insecurity': the perception of fundamental threats to life and security. We are not aware of anyone else trying to do so. Here is the instrument that we now use:

Human insecurity scale variables: (range of scores 1-5)

1. To what extent do you fear for yourself in your daily life?
2. To what extent do you fear for your family in your daily life?
3. To what extent do you feel worry/fear not being able to provide your family with daily
4. life necessities?

5. To what extent do you worry/fear about losing your source of income or your family's
 6. source of income?
 7. To what extent do you worry/fear losing your home?
 8. To what extent do you feel worry/fear from displacement or uprooting?
 9. To what extent do you worry/fear for your future and your family's future?
 10. To what extent do you feel fear on your safety?
 11. To what extent do you feel fear on the safety of your family?
 12. To what extent does your family feel fear on your safety?
- Response options: not at all, a little, a moderate amount, very much, an extreme amount

We have also developed a 'humiliation measure'. This emerged from our experiences during the 2002 invasions of West Bank towns. I was on a hotline. From 1pm onwards I was receiving calls from people who needed ambulances and those wanting to get supplies of cough syrup, mattresses, baby milk, food, bread, etcetera. During that time, the Israeli military was stopping ambulance drivers and prohibiting them from taking seriously injured people to hospital. We asked six of these ambulance drivers to come and talk about their experience in class to our students. When they came, the most important thing they talked about were experiences of humiliation. And when they talked about this, they cried and we all cried together. The humiliation that they felt for not having been able to take their patients to hospital was the most important aspect of their experience. They spoke of this as most humiliating, as if they had been stripped by the Israeli army in public completely bare. They spoke of an intense sense of humiliation and loss of dignity.

It was from this experience that we began to build our scale. As we studied, it turned out that there are two types of humiliation. There are distinct words for these different types in Arabic, but I don't think there are obvious translations in English. One relates to a personal injury on your dignity, while the other relates to a collective humiliation that appears to be much more difficult to get over. An example, of collective humiliation are the daily experiences of Palestinians at checkpoints where it is not only you being stopped from crossing and being asked for ID, it is also looking around you and seeing professional people, doctors, senior people, etc, all going through the same thing.

In some of our studies we have asked people how many times they have:

- Been publicly humiliated themselves
- Saw stranger being humiliated
- Saw family member humiliated
- Saw friend/neighbour humiliated

In other studies we have asked:

How often have you experienced the following at the hands of the Israelis: father or other person close to you was humiliated?

Response categories: never, once, 2-3 times, up to 10 times, more than 10 times

In all our studies, we have found that there is a link between humiliation and subjective health outcomes.

We are now very interested to know the extent that such a 'humiliation measure' might be relevant in other contexts, for instance for Aboriginal Australians or other oppressed peoples. I have a sense that Aboriginal people are a people who historically lived with great dignity on their lands. Would it be relevant to find ways of measuring the humiliations and destruction of dignity that people are currently experiencing and how experiences of humiliation may be linked to health outcomes? We think it might prove significant. I think that kind of research might be relevant to so many people who have been colonised. We are interested in comparative studies. We need to compare and exchange ideas. This would be very good for us, and perhaps for others also.

That sounds fantastic to me. Can I ask you two further questions? The first is a more technical question about the research itself and how you go about developing these measures. We would really like to encourage this sort of innovation ... can you say more about how you go about this? And secondly, do you think it'd ever be possible to generate measures for social and psychological resistance, or whatever this might be called in Palestine. You have developed a measure for humiliation, would you be interested in measuring factors that enable the reclamation of pride or dignity ... do you think this would be a useful idea here or elsewhere?

In relation to your first question, we have a routine now which we have developed and we like it because it bears results. First you must be an astute observer. We're constantly observing, even within our own homes. We are critical observers. Secondly, we constantly read the literature, but we don't accept this literature easily. We don't assume it is relevant for a Palestinian context. So we are critical observers and critical readers. Through these processes, if we then observe a local phenomenon that has not been addressed, or if it's being addressed in unhelpful ways (for instance the trauma industry's response to Palestinian experience), then we start our field work. It's a bottom up process. We hold focus group discussions and interviews with a range of different types of people. These qualitative methods, which have a different epistemological perspective than standard anthropology, are tools we use in order to develop our own measures and questionnaires.

We derive from the interviews the measures that we will then use in questionnaires. Often we use colloquial Arabic, not classical Arabic, because especially women who are not educated do not understand classical Arabic. And we really care about semantics and idioms. We make sure we are using local idioms of distress. In fact, it is from local idioms that we derive theory. Listening to and analysing the words and phrases that people ordinarily use to describe their experience is what gives us the theory. This creates the frame from which we develop an instrument. We then pilot this and use factor analysis in conjunction with cultural analysis. And then we do a survey and publish it.

At first it was very difficult to publish the results of these studies because reviewers would ask 'where was this instrument validated?' But we would answer, 'We created and validated this instrument. We have proved that it is valid in our context'. By the way, most of the so called 'scientifically' 'validated' international instruments that we have tried are of no use here. There is just no way that most instruments developed in the USA are relevant in a Palestinian context. With time, however, our approach has begun to be acceptable. This is particularly true since we have

begun publishing regularly in the Lancet. Richard Horton, the Editor, has opened big doors for us and our research.

In relation to your second question, we've been working on the issue of so-called resilience. As I mentioned earlier, we have come to recognise and research the significance of humiliation. On the obverse we have become interested in 'resilience', although there's been an overemphasis on universal resilience in the literature and much of this is quite problematic. We believe that resilience is a very fluid term. It varies tremendously from culture to culture and can even vary within the same culture. Here in Palestine, what may be called resilience elsewhere, we like to call the capacity to endure and resist.

That's a beautiful phrase.

We believe it is this capacity to endure and resist that gives you dignity. How do you redress your humiliation? By the capacity to endure and resist. The reason we're interested in studying local and particular forms of resilience is because this is what gives dignity. This is the redress of humiliation.

So are you going study this capacity to endure and resist? Will you seek to use the same processes that you described earlier to do this?

We would like to. As we're utterly dependent on international aid for research money, we might need to win the lottery! But yes, if we could carve our own research agenda then this is what we would study next.

Wouldn't comparative studies about the capacity to endure and resist be intriguing?

That would be lovely. We always have hope. One thing that gives Palestinians the capacity to endure and resist, and I don't know if it's the same with the Indigenous peoples of Australia, is that we know that the moral imperative is ours. Here, we feel so strongly that there's been such an injustice done to us and the collective moral imperative to right this wrong gives our people a confidence and dignity that buttresses our capacity to endure and resist. That's one aspect we would like to study. How can this moral imperative be reinforced? What health outcomes are linked to it? Perhaps Aboriginal Australians would also be interested in this question?

Of course, there are other aspects to our capacity to endure and resist. Over time we have developed what we call a 'pessoptimist' perspective. Emile Habibi (1974) wrote about this in a story called 'Saeed: The Pessoptimist'. Palestinians are both optimistic and pessimistic at the same time. I think this mindset would be worth studying. What are the mindsets that buttress a capacity to endure and resist? How can these be supported? What would the health outcomes be as a result?

There are other projects too that we are interested in. For instance, we would like to build a scale that relates to daily life ambiguities and uncertainties and see how this correlates with health outcomes. Here in Palestine, we don't know if we're going to wake up the next day and be able to go to work. We don't know if we can get our children back from school okay. We don't know if our husbands will come back safely. There is so much we just don't know from day to day. Everything is up in the air. These

are the issues which affect our lives. We want to do the research to demonstrate the ways in which these issues are linked to health outcomes.

We want to make research that is relevant to us. I've been exposed to so much political violence. I've witnessed so much destruction around me. I've witnessed how my child has been traumatised. I will never forget these things. Our research is from the people, by the people and it is for our people. It's always from the bottom upwards.

Our work relates to Foucault's (1976) call for an 'insurrection of subjugated knowledges' (p.81). That's the heart of what we are doing. As Palestinians, we are insisting that we can contribute to knowledge from our own lens. We are seeking to make a particular contribution to knowledge, a knowledge that can be put to work to improve people's lives and their health. And for us, health cannot be separated from justice.

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