PSYCHOLOGY MISCELLANY

No.28 - October 2011

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ISSN: 1754-2200

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1. STUDYING VULNERABLE POPULATIONS

1.1. INTRODUCTION

The ethics of research are seen as crucial because of the historical examples of abusive research. The most extreme case being the experiments on Jewish prisoners in Nazi concentration camps during World War II [1] [2]. While a peace-time infamous example is the deliberate infection of 400 African-American men with syphilis in the 1932 in the Tuskegee Study, USA, and then the withholding of treatment to see the effects of the disease over time (not ended until the 1972; Shaver et al 2000) [3]. Other lesser known and less extreme examples show that vulnerable individuals have been exploited for the sake of research (in these examples, medical research) (Park and Grayson 2008).

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[1] After World War II, the Nuremberg Code 1947 outlined ten standards for research with humans including voluntary informed consent, and avoiding all unnecessary physical and mental suffering. These ideas were developed in the Declaration of Helsinki in 1964 (Gray 2009).

[2] Seltzer and Anderson (2001) outlined how the systematic collection of population data by Governments has been used in famous cases of human rights abuses in the recent past.

[3] Shaver et al (2000) found that knowledge of the Tuskegee Study still resulted in less trust of researchers by African-Americans (and some Whites) in a survey in Detroit in 1998-9. Four key questions were asked:
i) "Have you ever heard of the Tuskegee Syphilis Study or the study of syphilis in black men?" - 81% African-American respondents had and 28% of White respondents.
ii) "How did the men in the Tuskegee Study get syphilis?" - 76% of African-American and 59% of White respondents answered correctly, by medical injection.
iii) "Will what you know about the Tuskegee Study affect your decision to participate in a medical research as a study subject in the future?" - 46% of African-Americans and 34% of Whites said "yes".
iv) "How does what you know about the Tuskegee Study affect your trust in medical researchers?" - 51% of African-Americans and 17% of Whites said less.

1.2. WHAT IS A VULNERABLE POPULATION?

Silva (1995) defined a vulnerable population as individuals who have "diminished autonomy due to physiological/psychological factors or status inequalities" (quoted in Moore and Miller 1999). Moore and Miller (1999) extended this definition to include "those who lack the ability to make personal life choices, to make personal decisions, to maintain independence, and to self-determine. Vulnerable individuals are therefore more likely to experience real or potential harm and require special safeguards to insure that their welfare and rights are protected" (p1034).

Vulnerable populations in the research literature includes foetuses, children, pregnant women, students, employees, older adults, stigmatised individuals, those with a disability (physical or learning), homeless, and institutionalised adults (Moore and Miller 1999) [4] [5].

So, a vulnerable research population is "a group of participants who are either unable or less able to protect their own interests... [and] Although some may perceive this implication as stigmatising or labelling, such is not the intent. Rather, the intent is to ensure that researchers take extra precautions and a more rigorous approach – whether these are to evaluate capacity, to meet particular information needs or to ensure that any decision to consent or refuse to participate in a given research protocol is voluntary" (Hawryluck 2004 p225). Hawryluck was speaking in relation to individuals dying from terminal illness.

However, Berry (2004) argued that it was a mistake to view such individuals as vulnerable for research purposes, and "a potential barrier to doing research that will help improve the quality of care provided to dying patients" (p223). The person should be treated as an individual in terms of assessing their ability to participate in research. Rhodes (2002) observed that: "Declaring socially defined groups of people... as 'vulnerable' and therefore in need of benevolent intervention and protection shows the opposite of respect for their autonomy... making such judgments about entire social groups smacks of prejudiced discrimination and disrespect" (quoted in Berry 2004).

How to study end-of-life without the researchers

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[4] Moore and Miller (1999) pointed out that some individuals are "doubly vulnerable" because they simultaneously experience more than one of the vulnerability factors (eg: homeless children; older adults with learning disabilities).

[5] Vulnerable populations can also be "hard to reach" populations (appendix 1A).

saying, in so many words, we are only interested in you because you will be dead soon, particularly if the individual is not aware of this, for some reason? The most ethical answer is to gather data from relatives and other informants ("proxy respondents" - indirectly from the target respondent) (Lloyd et al 2011). Another possibility is to collect information in particular locations, like hospices or nursing homes, which suggest to the participants that they are close to death (Lloyd et al 2011).

Anderson and Hatton (2000) emphasised the importance of nursing staff being able to meet the needs of all members of society. Serving needs is based on knowledge about the individual or group. But this is limited for certain groups "because circumstances can make it difficult to recruit vulnerable individuals into a study, to ensure their informed consent, and to contend with the data obtained" (p244).

1.3. RESEARCHING VULNERABLE POPULATIONS

There are a number of issues related to studying vulnerable populations:

- Locating the individuals, particularly for hidden groups (as in illegal behaviour).

- Vulnerable populations often inhabit places where researchers/academics usually do not or cannot go.

- "Vulnerable persons face pressing socio-economic needs that limit the time and energy they have available for research participation" (Anderson and Hatton 2000).

- Differences between vulnerable people and researchers in terms of, for example, socio-economic status, education, language, ethnicity. "These differences have consequences for how the researchers and participants view the importance and purpose of research. These differences can also have an impact on their communication" (Anderson and Hatton 2000).

- The motivation to participate - "In Anderson’s (1996) research with homeless women, the informed consent process included telling participants that although they would not benefit from taking part in the research project, other women and girls might benefit from the knowledge gained. Several women were emphatic that they would participate if it meant that even one woman would be helped in the future" (Anderson and Hatton 2000 p245).

Smith (2008) discussed the problems related to researching the marginalised group of women who used drugs during pregnancy, had a live birth, and continued to use them.

i) The ability to give informed consent could be impaired by their drug use.

ii) Protecting anonymity [6] and confidentiality where sensitive information involved, like child protection issues.

iii) Recruitment problems - eg: hard to find population through fear of authorities; barriers to research participation like limited income for travel to researcher or low level of literacy as social disadvantage is often associated with drug use.

iv) Risk of exploitation - "Zealous researchers undertaking commissioned research on which their job depends may not have the welfare of individuals as their prime concern when seeking an appropriate sample size for the chosen methods of inquiry" (Smith 2008 pp253-254).

Research in the area of HIV/AIDS is seen as working with a vulnerable population. But this is compounded if the participants are sex workers, and if Western researchers are investigating in Africa, say. In 2004-5, trials to test the use of anti-retroviral drug tenofovir with individuals not diagnosed with HIV/AIDS as a prevention funded by the US government and private donors were stopped. Activists had campaigned against the studies because, it was argued, the participant sex workers were not being treated ethically. In Cameroon, for example, it was argued that the sex workers had not been given the opportunity to give adequate informed consent (Mills et al 2005).

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[6] Tilley and Woodthorpe (2011) explored the problems of anonymity of participants in the 21st century, particularly with the growth of the Internet, and the demands upon academic researchers. "On the one hand, to enhance their credibility the qualitative researcher needs to be able to demonstrate their practical use of established ethical codes of practice, illustrate their conceptual knowledge of ethics and associated constraints, and show themselves to be a researcher of responsibility and integrity. On the other hand, they are increasingly required to disseminate widely, get as much information 'out there' as possible, be involved in knowledge transfer and show their value for money as an academic capable of meeting the various demands imposed upon them. They also need to be demonstrating that they are accountable to funders and produce real-world 'results' that can be used in policy and organizational contexts. Necessarily, this can mean identifying research sites and participants – which may conflict with the expectation that the research is anonymised" (p208).

1.3.1. Motivation to Participate in Treatment Research

Individuals with particular medical conditions agree to participate in research on new treatments for different reasons including altruism (ie: findings will help other sufferers) and selfishness (access to the new treatment), and they withdraw early on for practical reasons like heavy work schedule, or concern about potential risks of treatment (Lowton 2005).

The decision to participate in such research by vulnerable individuals can be viewed as a risk decision. Bloor (1995) described risk decisions based on two continuum:

i) Habituation-calculation - Habituation relates to risks that are common and require little thought each time (eg: crossing a busy road). Calculation refers to rarer risks that require a careful conscious assessment of costs and benefits.

ii) Constraint-volition - Individuals will be constrained in some risk decisions by, for example, the available options, and, in other cases, have greater freedom or choice.

Lowton (2005) interviewed 31 adults (aged 18-40 years old) with cystic fibrosis (CF) [7] about their motivation to participate in research related to their condition. Survival to later adulthood is not guaranteed (eg: mean age 28-32 years old; Lowton 2005), and so such individuals are valuable to researchers.

Requests to give a blood sample, for example, which is common with CF sufferers, was viewed routinely (as in Bloor's habituation), while research that required a delay in trying to start a family in order to participate would involve more thought (as in Bloor's calculation).

In terms of constraints, the willingness to participate in research can be limited by time available (ie: working or not), for example, as well as worries about health: "The knowledge of already having outlived the survival age predicted for CF patients as a group and the likelihood of declining health state with increasing age was a significant health constraint on patients in their late twenties. The thought that something might 'go wrong' through participation in research projects and lead to damaging the health that they considered to be currently good and were so carefully controlling was enough to stop patients from participating..." (Lowton 2005 p1859). An example of volition would be individuals choosing to participate to help others.

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[7] CF is a genetic condition that affects the lungs, and, currently, there is no cure.

Agreement to participate in research can also be influenced by simple things like trust or liking of a particular doctor. For example, "Clare" said: "One [doctor] I really wanted to help. He was doing a diabetic one [research study], a Chinese chap and he was really nice and non-pushy, and I almost wanted to do it because of his attitude, but the other one [doctor] I didn't like. [Later] The other one was [doing] things up your nose and stuff and I really don't like the doctor anyway, so I just thought, 'Oh, no, nothing about that [study] attracts me to wanting to do it'" (Lowton 2005 p1858).

1.4. INFORMED CONSENT

Wiles et al (2007) individually interviewed 31 researchers involved in studying vulnerable populations, and ran six focus groups with thirty-five more experienced researchers. There were no consensus about the practicalities of gaining informed consent with vulnerable individuals. A number of points emerged from the analysis.

i) Researchers may not give as much information about the research as the participants want because it not known what will happen.

ii) Concerns by researchers of not overwhelming vulnerable individuals with too much information.

iii) Participants may not take the time to read the information given anyway.

iv) Individuals can be keen to participate whatever. One researcher observed: "one of the problems was that... people would cut us off and say 'yes I'm happy to participate' before we had chance to finish [reading out the introductory information]... people often love to participate in research, specifically I think when they are being asked about their drug use, drug users can often be very keen to talk about their drug use" (Interviewee 5).

v) Misunderstanding by the participant. One researcher recalled: "despite having a written information sheet that explained the study really carefully to people... it was clear they thought I was a social worker or some sort of an appliance officer... however much time and attention that you explain what research is, people interpret what you do in a number of different ways. And some people see it as a form of therapy, even if you don't intend that to be the case" (Focus Group 1).

vi) How to convey the information to participants, particularly those with limited reading skills, like children or adults with learning disabilities.

vii) Asking for a signature on a consent form is good practice for researchers, but can be problematic for participants (eg: illiterate individuals). "Participants may fear that signed consent forms could make the information they provide traceable to them which may put them at risk of physical harm (in the context of research topics such as domestic violence) or vulnerable to potential investigation and prosecution by the criminal justice system (in the case of illegal activities)" (Wiles et al 2007).

viii) How appropriate is the use of "rewards" for participation, and does it reduce the voluntary nature of consent?

ix) The need to seek consent as ongoing rather than once and for all, and so individuals have the right to withdraw at any time. "However, researchers have noted that it is common, particularly for some groups, to be reluctant to state they do not want to continue being involved with a project. So, for example, children might find it difficult to tell an adult that they no longer want to participate in a study or that they do not want to answer a particular question. The same issue can apply to people in a range of contexts because of the power relations that can exist between the researcher and the researched or simply a lack of awareness that they can say no to something they have previously agreed to. Researchers noted that they needed to be vigilant to participants' unspoken expressions of reluctance to continue to participate during data collection, such as an apparent lack of interest or irritation with the data collection. In research with children and people with limited communication, researchers have used 'stop' cards that participants can hold up if they do not want to answer a particular question or no longer want to participate..." (Wiles et al 2007).

x) The level of consent varies depending on the method used. For example, with covert observation in public places, it is more difficult to gain. Furthermore, one researcher noted that "in certain methodologies... requiring written informed consent seriously damages the method that you're going to pursue... Any recording or observation that requires spontaneously occurring behaviours or speech, and I'm thinking particularly things like conversation analysis and ethnography... both of those are highly problematic" (Focus Group 1). A researcher in another focus group was critical of this: "maybe some research just can't be done... If you can't get informed consent then there's maybe a good case for saying it can’t be done... I can't think of a piece of covert research I'd be happy to [do]" (Focus Group 2) (appendix 1B).

1.5. PROTECTION FROM HARM

Clark and Sharf (2007) explored particular issues involving qualitative methodology: "As qualitative researchers, we choose to enter the lives of others — especially those in vulnerable situations and at pivotal points of time — with intentions of both giving voice to the depth and richness of individual experience and accomplishing socially relevant changes within the contexts examined. To fulfil these goals, we choose topics about which we feel passionately, seek triangulated methods, attempt to establish partnerships with those studied, and position ourselves openly in approaching the research scene and interpreting our observations and other materials collected. In engaging in this complex, rigorous process of inquiry, it is essential that we recognize that qualitative research is a deeply personal enterprise" (p399). Qualitative research is different to quantitative research for this reason: "Our shared humanity is the ground on which we and our participants stand. It not only makes understanding possible between us, it is the basis of our relationship together, and it is that relationship that is the heart of the matter" (p400).

Clark and Sharf (2007) wanted to highlight that during such personal research, certain information becomes available to the investigators which has consequences for the informants and others. What to do with such information? Is it best to tell the truth? For example, Lieblich (1996) reported the case of a mother reading her daughters' "stories" from the interviews that portrayed her as a neglectful mother. Or, while investigating sistering, Mauthner (2000) was given personal information about one sister by an interviewed sister, but the former had not shared that information in her interview. The researcher chose not to use information not given by the person involved (Clark and Shafer 2007).

Another ethical dilemma is the disclosure of information not directly related to the interview topic. For example, a woman in a health-related interview starts talking about her daughter's sexual abuse by the husband. "Feeling the warmth, undivided attention, and sincere interest shown by skilful interviewers (something we rarely experience in daily life), participants can easily reveal intimate details about their lives which they may later regret having said" (Kirsch 1999 p29 quoted in

Clark and Shafer 2007 p402).

Clark and Shafer (2007) presented four ethical dilemmas they encountered in relation to the consequences of telling the truth in their research.

i) "When the truth hurts" - The researchers see unflattering information about a patient in her medical records, and the patient, who has consented to the viewing of the records, wants to know what was written about her. The solution: "We decided not to re-contact this individual, and though we still felt a little guilty about the matter, on balance, we concluded that we had done the best thing having taken all the circumstances into consideration" (p405).

ii) "Seduced by the caring interviewer" - During research with a female prison inmate, information is confided that is very intimate and placed the interviewee in danger if made public. The researcher did not use that information, but "the issue remains about the intimacy created in this kind of interview situation that itself can elicit truths not intended to be shared" (p407).

iii) "Disagreeing with the Institutional Review Board" (IRB) - In a study of opiate addicts via the Internet, the IRB wants to hide the institution's identity through concern over association with certain websites. In other words, the researchers had to hide their identity as researchers during electronic interactions, which involved deception from the researcher's viewpoint. The only way for the research to proceed was to accept the IRB's demands.

iv) "Hearing stifled voices behind the iron curtain" - An interview with a political dissident contains information critical of the government. Publication of the interview in the researcher's home country would be risky in many ways for the interviewee and his family. The researcher in question admitted: "even changing identifying details would not protect them, as my own movements on that trip were certainly known to the authorities. I could choose fiction, as I in fact have done here, creating a story of my own that holds enough but not too much (I hope) of the truth yet carrying sufficient moral purpose of the original to make it worth the telling. But that falls short, too. How can a cause that's masked be served? I don't have those answers. I remain unsure what to do, and this dilemma remains unresolved" (Carolyn Clark in Clark and Shafer 2007 p412).

1.6. STUDYING SPECIFIC GROUPS

Locher et al (2006) described two ethical issues related to studying homebound older adults:

i) Therapeutic misconception where participants mistakenly believe that they will receive some form of treatment as part of the research project.

This is more likely if health care professionals have recruited the participants. "Persons may want to please their health care provider by agreeing to participate, or they may believe they will get better care from their health care provider by participating. Conversely, persons may be concerned that their care may be threatened if they refuse to participate... Others may agree to participate because they are lonely and lack social contact. Lastly, home health patients who are socially isolated may, more than other patients, see research as a means to get easier access to health care" (Locher et al 2006 p161).

ii) Researcher role conflict where the researcher is expected to perform different roles (eg: researcher vs physician). A researcher is meant to be objective, while a physician is expected to put the patient first.

> Researcher role conflict is especially likely to occur in the home environment, when in the course of investigation the researcher becomes aware of something that is immediately or potentially harmful to the study participant. On the one hand there is the obligation of the researcher to remain objective and not do anything that could interfere with the data or with the results of the study, while on the other hand there may be an obligation as a health care provider or simply as a citizen to act in response to perceived abuse, neglect, or exploitation of the study participant... [Furthermore] Research conducted in the home allows the investigator to be privy to much information that he or she would not have access to if the research was conducted in another setting or over the phone. As a consequence, the researcher may be more likely to be a witness to something that is threatening to the participant's health or life, including elder abuse. This is not an unusual occurrence because homebound older adults may be especially vulnerable to elder abuse due to their increased social isolation, physical impairment, cognitive impairment, and dependence on others for care... (Locher et al 2006).

1.6.1. Domestic Violence

Sullivan and Cain (2004) observed that: "Although no researcher would intentionally set out to re-victimise their study participants, emotional or physical harm could still occur unless adequate protections are put in place to minimise this risk" (pp603-604).

Ellsberg and Helse (2002) explored the ethical issues involved in studying domestic violence among women who reside with the perpetrator [8].

i) Minimising harm - The women may be vulnerable to attack if the partner finds out that she has been telling someone else about what happens in the relationship. The solution is to hide the nature of the research (eg: as a women's health study) and/or the answers given from the partner. In one study in Zimbabwe, a male field-worker engaged the husband in lengthy discussions about purchasing a chicken, while a female field-worker interviewed the wife.

ii) Minimising participant distress - Interviews on sensitive topics can produce powerful emotions. Interviewers can be trained to deal with such reactions, but also to know when the interviewees want to tell despite the pain involved.

iii) Minimising harm to the researcher - Ellsberg and Helse (2002) quoted this example from research in Nicaragua (Ellsberg et al 2001):

> [The experience] that most affected me was with a girl my age, maybe 22 years old... She told me all about how her husband beat her while she was washing clothes in the back patio. Her mother-in-law would spy on her and tell her son things so that he would punish her. She was very afraid, and her voice trembled as she spoke, but she really wanted to tell me about her tragedy. She kept looking over to where her mother-in-law was watching us. She asked me for help and I told her about the Women's Police Station. When her mother-in-law got up to go to the latrine, I quickly gave her a copy of the pamphlet and she hid it. She thanked me when I left and I ended up crying in the street, because I couldn't stand to see such a young girl being so mistreated (p1599).

As well as the emotional risk, researchers can be attacked by the perpetrators of the domestic violence.

iv) The benefits of "giving voice" - "Significant anecdotal evidence suggests that research participants welcome the opportunity to tell their stories if they are asked in a sympathetic and non-judgmental way" (Ellsberg

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[8] This was based upon the authors' experiences with the WHO Multi-Country Study on Women's Health and Domestic Violence Against Women, and the International Research Network on Violence Against Women.

and Helse 2002 p1602).

v) Reporting to the authorities - Many countries require the mandatory reporting of illegal behaviour to the authorities, particularly in relation to child abuse. "Such laws raise difficult issues for researchers, because of conflicts between ethical principles: respect for confidentiality, the need to protect vulnerable populations, and respect for autonomy. Most researchers agree that, in the case of women, the principles of autonomy and confidentiality should prevail, and researchers should do everything within their power to avoid usurping a woman’s right to make autonomous decisions about her life. Decisions are more difficult in cases of child abuse, and especially so in settings where there are no effective services to assist troubled families, or where reporting could put a child at even greater risk, for example, by alerting an abuser to the possibility of being exposed" (Ellsberg and Helse 2002 p1603).

Sullivan and Cain (2004) focused on the practical issues:

a) How to first contact the women without notifying the abusers - This assumes that the women are living with the abusive partner rather than interviewing those in shelters or refuges. For example, Langford (2000) used newspaper advertisements with an answering machine that asked the women to leave a telephone number and the time best to call. Then, when telephoned, the women were immediately asked if it was safe to talk.

From their fifteen years of working with "survivors" of domestic violence, Sullivan and Cain (2004) advised "that 'first contacts' be as vague as possible until there is some assurance that a woman is safe to hear more about the study. For example, letters should be written with the understanding that assailants, friends, family, or neighbours might read them. Therefore, they should not mention domestic violence or potential monetary compensation for participating in a research study. If a perpetrator sees that this is a study of domestic violence, he may become violent and/or prevent the woman from participating. If the perpetrator sees that money can be made from the study, on the other hand, he might coerce or force the woman into participating. Letters might ask women to participate in something clearly for women only, such as a 'women's health study'" (p605).

b) Where data collected - Will the women come to the researcher, the researcher go to the women, or a neutral venue is used?

c) Protecting the women's safety before, during and after data collected - eg: the woman is questioned alone to allow them to speak honestly, or to prevent information being passed back to the abuser from another person present. Also abuse can continue (if not escalate) after the relationship has ended (Sullivan and Cain 2004).

d) Safely re-locating the women in longitudinal research - "For example, at one time point, a woman might insist that contacting her at any time of the day or night will be safe because she has no intention of ever seeing her assailant again. Yet by the next contact, she could very well be living with him or he may have gained access to her home or answering machine. It is, therefore, critical to ask women at each time point how best to contact them in the future but to also always take certain precautions when contacting women, regardless of their situations at prior interviews" (Sullivan and Cain 2004 p609).

An ethical dilemma arises in studies with intervention and control groups. How to deal with the women in the control group? Sullivan and Cain (2004) suggested offering some help, but not the full assistance of the intervention group.

1.6.2. Holocaust Survivors

Over fifty years after World War II, survivors of the Holocaust are moving into later life. These Jewish individuals, who experienced the Nazi concentration camps, have been studied over the years. Studies show a wide range of findings about them - more psychological impaired than controls versus better coping skills and social adjustment than controls; lower or higher subjective well-being than age comparisons. "Some survivors report a high level of psychological distress, while others, who were exposed to similar experiences, report few, if any, symptoms" (Hantman et al 2003 quoted in Greene 2010 p412). A mixed picture emerges (Shmotkin et al 2003).

Older Holocaust survivors still alive are not representative of the whole population of Holocaust survivors. These individuals are the "surviving survivors" (Shanan 1989), and probably show the most resilience and psychological adjustment. Shmotkin et al (2003) set out to investigate this idea.

Using participants from the Cross-Sectional and Longitudinal Aging Study (CALAS), which follows older Jews in Israel (begun in 1989), three study groups were formed:

i) Holocaust survivors - 126 individuals originally from Europe who defined themselves as Holocaust survivors, and immigrated to Israel after 1945.

ii) Pre-war immigrants - 206 individuals from Europe who arrived in Palestine/"pre-state Israel" before 1939.

iii) Post-war immigrants - 145 European immigrants to Israel after 1945 who did not define themselves as Holocaust survivors.

The mean age of all three groups was 83 years old. All participants answered questions read to them by the interviewers about physical and subjective health, daily functioning, mental health and cognitive functioning, lifestyle, life events and stress.

The survivors fared worse than the pre-war immigrants only in terms of cumulative life-event distress (not surprisingly). Both groups who immigrated after 1945 were similar with the non-Holocaust survivors reporting many stressful life events related to World War II and immigration.

Overall, a positive picture emerged of the ageing survivors (relative to their contemporaries): "As survivors, people who have endured a trauma gain a hope for recovery and often achieve a newly restored life. The current study of older survivors suggests that handling the past trauma and maintaining a new life after it are ceaselessly intertwined endeavours" (Shmotkin et al 2003).

Qualitative interviews are better able to explore the individual resilience of survivors [9]. For example, Greene (2002) interviewed thirteen such individuals who talked about overcoming the extreme events to live afterwards.

While Greene (2010) reported open-ended interviews with 133 survivors in the USA. The resilience of survivors was aided by:

- Pre-World War II protective factors - eg: positive family environment.
- Resilient behaviours during World War II - eg: trying to survive in family groups.
- Resilient behaviours after World War II - eg: "normal" life events like having children.

Exploring the resilient behaviours during World War II, further examples included:

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[9] Resilience can be defined as the adaptation to extraordinary circumstances and the achievement of positive outcomes in the face of adversity (Fraser 1997).

i) Resolving to live.

ii) Obtaining food and shelter - eg: tricking concentration camp guards to get extra food.

iii) Choosing survival strategies - eg: one survivor said: "My sister and I used to get up early at dawn and unravel older sweaters and knit clothes for farmers and their children. Then when the people would come to us we could barter them off for food" (Greene 2010 p419).

iv) Keeping family ties.

v) Making friends.

vi) Turning to others and banding together.

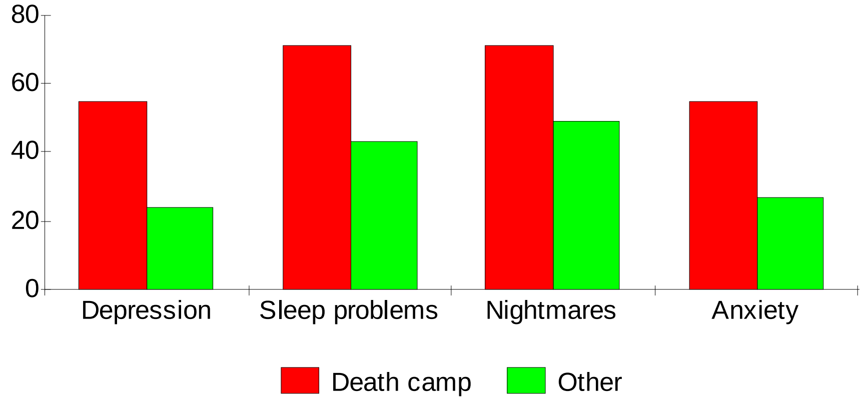
The most important protective factor in terms of survival and subsequent resilience seems to be social support.

Many studies of Holocaust survivors have concentrated on clinical populations (ie: those seeking help for mental health problems). But these individuals may not be representative of the whole Holocaust population.

Robinson et al (1990) interviewed 86 survivors over 60 years old living in Israel. They were a non-clinical population of individuals who had testified at Yad Vashem, the Holocaust Martyrs' and Heroes' Remembrance Authority in Jerusalem, which documents the Holocaust since the 1950s. One hundred and twenty names were randomly chosen from the records. Those who agreed to participate were divided into four groups - survivors of death camps, survivors of slave labour camps, those who were in hiding during World War II, and partisans/resistance fighters.

Sixty percent of the interviewees reported current physical illness connected to the Holocaust, and 75% felt that they were still suffering because of it. This included nightmares with Holocaust content and other sleep disturbances, nervousness and anxiety, headaches, and guilt feelings. Survivors of death camps reported significantly more symptoms than the others (eg: current depression - 55% vs 24%) (figure 1.1).

Though the survivors still suffered in many ways, most had managed to live "normal" lives since World War II (eg: 91% had a "warm" family atmosphere). "The survivors' strong urge to cope and to be successful is connected for many of them to their need to give meaning to their lives, to the fact they were left alive, and others were not. This is also a form of coping with survivor guilt, and feeling a duty to their loved ones who perished in the Holocaust - to their father, mother,



(Source: Robinson et al 1990 table p313)

Figure 1.1 - Percentage of survivors currently reporting different problems.

brothers and sisters who perished - that the survivors are fulfilling their expectations. The survivors also try, partly consciously and partly unconsciously, to fulfil the testament of those who perished, by hard work, devotion to their families, raising children and devotion to the State of Israel" (Robinson et al 1990 p314).

1.7. WHO SAYS VULNERABLE?

Russell (1999), talking about a project to interview socially isolated older adults which struggled to recruit interviewees, noted the construction of the individuals as vulnerable. One social worker said to the researchers: "the content of what you want to talk about may be very threatening... To be socially isolated is a label that is being put onto older people. It implies that there is something wrong with them. One has to be very careful. Some of these people would feel like a failure. They also fear it so much they would not even be able to talk about it. It is just so debilitating. It could just tip the balance".

Though these are valid concerns, Russell (1999) found that the participants were far from vulnerable in this way. They were "active participants" in "using" the interviews for their benefit. For example, to tell the interviewer information that is kept hidden from family and professionals. One recently bereaved man admitted: "When I was drinking I'd take the crates of empty bottles out of here and share them around in other people's bins in the morning, so that my daughters would not see them... I have told you more than I would have told [the social worker]. I never told her that I am drinking".

In other cases, the interviewees attempted to prolong the interview, or to talk about the topics that interested them. Quoting from one interviewer's field notes: "The 'interview' with Miss M was mostly stream of consciousness, all floodgates open. I did not have a chance to ask a first question. Miss M started talking while I was still looking for a seat ... I was able to place a few questions as she was taking a breath before the next flood of words. She had her own agenda and was not interested in complying with mine!" (Russell 1999).

Russell (1999) emphasised: "A reading of the interview as a social practice in which even vulnerable people may choose to participate - often with relish - can also shift the ethico-political grounds of discussion. If respondents are seen as active subjects rather than disempowered victims in the interview situation, it follows that they may participate with a variety of preformed or emergent purposes".

1.8. TOO MUCH CONCERN

Park and Grayson (2008) noted the downside of too much concern about the ethics of studying vulnerable populations: "Although concern for protecting these vulnerable populations is clearly necessary and important, it also has negative side effects. Most notably, by protecting vulnerable populations, we might have stifled adequate research involving these very subjects" (p1103).

Clinical trials offer free medication or treatment as the incentive for participation, and it is possible that economically disadvantaged individuals might be especially enticed by this. Is this a form of duress or coercion? Are the individuals freely choosing to participate? On the other hand, "Is it better to receive some care under the umbrella of trial-based therapy rather than none at all?" (Park and Grayson 2008).

Park and Grayson (2008) finished with a warning about the concept of vulnerable individuals (in medical research): "Acknowledging the vulnerability of certain populations is critical to ensuring that clinical research is conducted in an ethically appropriate way. However, whether our current definition of vulnerable is appropriate is controversial. A frequent consequence of the current definition is that the so-called vulnerable populations are automatically excluded from trials. This blanket exclusion limits their autonomy and in many ways only serves to increase their vulnerability because their medical care cannot be based on evidence-based research, as is that of the general non-vulnerable population" (p1106).

1.9. APPENDIX 1A - "HARD TO REACH" POPULATIONS

"Hard to reach" populations, like transient and homeless individuals, intravenous drug users, sex workers, and incarcerated and institutionalised individuals, are difficult to study as the name implies. Such individuals are usually recruited through agencies and/or snowball sampling (Abrams 2010).

Snowball sampling is where a respondent is asked to recommend or introduce the researcher to other potential respondents, and the sample is built up that way. This produces a "referral chain" (Faugier and Sargeant 1997). It assumes that "hard to reach" individuals know each other. Thus, they are "not randomly drawn. They are dependent on the subjective choice of the originally selected respondents" (Black and Champion 1976).

There are different types of bias in snowball sampling (Faugier and Sargeant 1997):

- Some individuals will know more people than others.
- Individuals may exist in sub-sets (islands) knowing only those in their sub-set.
- Some individuals will be more likely to be "found" by the researchers than others (eg: popular individuals).

Biernacki and Waldorf (1981) pointed out that this "method is well suited for a number of research purposes and is particularly applicable when focus of the study is on a sensitive issue, possibly concerning a relatively private matter, and thus requires the knowledge of insiders to locate people for study" (quoted in Faugier and Sargeant 1997). Thus, it "relies on the behaviour or 'trait' under study being social and participants sharing with others the characteristic under examination" (Browne 2005).

Using agencies in recruiting participants can miss those individuals who do not seek help/contact, and may be the most extreme cases. This may be the case where criminal activity is involved.

In her doctoral research on the experiences of 28 non-heterosexual women, Browne (2005) admitted that 13 of them were "friends" ("women I would meet regularly in social settings and we considered each other to be 'friends'") prior to the study. The other fifteen were acquaintances or strangers asked to participate by women in the study.

"However, it is worth noting that non-heterosexual women are not a homogeneous group and we exclude people, including other non-heterosexual women, from our social networks. For my research women may have been excluded for a multiplicity of reasons, such as my not knowing a person well enough (if at all) or because of strained relations between women (for example, if they had gone through a break up). Although by definition snowball sampling does not include those outside of social networks, the situations may be more complex than individuals simply not knowing each other. Individuals who are excluded from social networks for any reason will almost certainly be absent from research accounts that employ these social networks. Moreover, it is difficult to assess who has been excluded when the group under investigation is 'hidden'" (Browne 2005 p52).

While studies placing advertisements in the "gay press" and around the "gay community" for gay, lesbian and bisexual participants misses those people who do not access these things and may not openly identify as gay, lesbian or bisexual. "Moreover, these studies categorise and define an individual's sexuality by their attendance at particular groups or by their reading material" (Browne 2005).

Also Browne (2005) noted that, for example, "too often studies of 'lesbians' and 'gay men' claim universal representativeness yet focus on the white, urban, middle class, young lesbian or gay man. This may in part be due to snowball sampling that relies on interpersonal relations and often a white, middle class, urban researcher's social networks. Consequently, and paradoxically, studies that use snowball sampling, whilst accessing hard to reach participants, can create other 'hidden populations'. This is not to say that there is a way of including all individuals. All recruitment procedures have the potential to exclude as well as include. Acknowledging the specificities (disadvantages?) of this sampling technique does not negate it; rather it enables a fuller understanding of the exclusions of the particular method" (p53).

1.10. APPENDIX 1B - COVERT RESEARCH

Covert research is "research which is not disclosed to the subject - where the researcher does not reveal that research is taking place" (Spicker 2011 p119). This can include observation of passersby in a public street where informed consent is practically difficult to obtain. But this is not the same as deception, argued Spicker (2011), where participants are told one thing while the research is interested in something else.

There are a number of situations where full informed consent cannot be obtained (Spicker 2011):

i) The observation is fleeting (ie: no opportunity to gain consent).

ii) The observation is anonymous as in a large public crowd.

iii) Gaining consent is burdensome, as well as impracticable - eg: observation of two drunk men fighting in public place.

iv) Gaining consent is intrusive. For example, in a public place, asking for retrospective consent for an embarrassing or "private" behaviour may be more "unpleasant" for the individual than to covertly observe the behaviour.

v) The researcher uses information outside the formal study - eg: prior knowledge of group or organisation being studied.

vi) Informed consent is gained from some individuals but not others (eg: in an organisation). Spicker (2011) quoted the example of using observations from a reception area before the formal interview with a manager at an organisation. The manager had consented to participate, but not necessarily the reception staff.

vii) Information becomes relevant after the event, and retrospective consent is not possible.

Covert research is seen as infringing the rights of participants, particularly in relation to privacy.

However, Spicker (2011) stated: "Research subjects do have rights, but they are not the only people with rights. They may have some say about the use of information, but not all information is under their control. They are entitled to privacy, but not everything is private. Undeclared, undisclosed research in informal settings has to be accepted as a normal part of academic enquiry" (p118).

In a wider context, Spicker (2011) used his "leaving from life" as an example of "ethical covert research":

> I work as an advisor, consultant and researcher, undertaking applied policy research to meet the needs of various agencies. The things I learn from each project add to the next. I use examples from previous research, practice and informal enquiries liberally in my teaching and writing. In the course of the last year, I have visited or discussed issues with government officials, benefit administrators, voluntary sector workers, employment advisers, welfare rights workers, community workers, campaigners, politicians, disability activists, journalists and of course academics. None of those discussions has been part of a formally constituted research project. Finding out about things – having conversations, forming networks, learning from people, and piecing information together – is part of my work. I do not generally do 'covert research' in the sense of

> deliberately constructing research that is intended
> to be concealed from view; but equally, there may be
> no point at which it would be opportune or appropriate
> to make an explicit disclosure about the process of
> research and how the information I glean might be
> used (pp130-131).

1.11. REFERENCES

Abrams, L.S (2010) Sampling "hard to reach" populations in qualitative research Qualitative Social Work 94, 4, 536-550

Anderson, D.G (1996) Homeless women's perceptions about their families of origin Western Journal of Nursing Research 18, 1, 29-42

Anderson, D.G & Hatton, D.C (2000) Assessing vulnerable populations for research Western Journal of Nursing Research 22, 2, 244-251

Berry, S.R (2004) For purposes of research, palliative care patients should not be considered a vulnerable population Clinical Oncology 16, 223-224

Biernacki, P & Waldoff, D (1981) Snowball sampling: Problem and techniques of chain referral sampling Sociological Methods and Research 10, 2, 141-163

Black, J.A & Champion, D.J (1976) Methods and Issues in Social Research Chichester: John Wiley & Sons

Bloor, M (1995) A user's guide to contrasting theories of HIV-related risk behaviour. In Gabe, J (ed) Medicine, Health and Risk: Sociological Approaches Oxford: Blackwell

Browne, K (2005) Snowball sampling: Using social networks to research non-heterosexual women International Journal of Social Research Method 8, 1, 47-60

Clark, M.C & Sharf, B.F (2007) The dark side of truth(s) Qualitative Inquiry 13, 3, 399-416

Ellsberg, M & Helse, L (2002) Bearing witness: Ethics in domestic violence research Lancet 359, 1599-1604

Ellsberg, M et al (2001) Researching domestic violence against women: Methodological and ethical considerations Studies in Family Planning 32, 1-16

Faugier, J & Sargeant, M (1997) Sampling hard to reach populations Journal of Advanced Nursing 26, 790-797

Fraser, M (1997) Risk and Resilience in Childhood Washington DC: NASW Press

Gray, D.E (2009) Doing Research in the Real World (2nd ed) London: Sage

Greene, R.R (2002) Holocaust survivors: A study in resilience Journal of Gerontological Social Work 37, 1, 3-18

Greene, R.R (2010) Holocaust survivors: Resilience revisited Journal of Human Behaviour in the Social Environment 20, 411-422

Hantman, S et al (2003) Long-term coping of Holocaust survivors: A topology Israel Journal of Psychiatry and Related Sciences 40, 2, 126-134

Hawryluck, L (2004) People at the end of life are a vulnerable research population Clinical Oncology 16, 225-226

Kirsch, G.E (1999) Ethical Dilemmas in Feminist Research Albany:

State University of New York Press

Langford, D (2000) Developing a safety protocol in qualitative research involving battered women Qualitative Health Research 10, 1, 133-142

Lieblich, A (1996) Some unforeseen outcomes of conducting narrative research with people of one's own culture. in Josselsen, R (ed) Ethics and Process in the Narrative Study of Lives Thousand Oaks, CA: Sage

Lloyd, L et al (2011) Researching the end-of-life in old age: Cultural, ethical and methodological issues Ageing and Society 31, 386-407

Locher, J.L et al (2006) Ethical issues involving research conducted with homebound older adults Gerontologist 46, 2, 160-164

Lowton, K (2005) Trials and tribulations: Understanding motivations for clinical research participation amongst adults with cystic fibrosis Social Science and Medicine 61, 1854-1865

Mauthner, M (2000) Snippets and silences: Ethics and reflexivity in narratives of sistering International Journal of Social Research Methodology 3, 4, 287-306

Mills, E.J et al (2005) Designing research in vulnerable populations: Lessons from HIV prevention trials that stopped early British Medical Journal 331, 1403-1406

Moore, L.W & Miller, M (1999) Initiating research with doubly vulnerable populations Journal of Advanced Nursing 30, 5, 1034-1040

Park, S.S & Grayson, M.H (2008) Clinical research: Protection of the "vulnerable"? Journal of Allergy and Clinical Immunology 121, 1103-1107

Rhodes, R (2002) Unsafe presumptions in clinical research American Journal of Bioethics 2, 49-51

Robinson, S et al (1990) The late effects of Nazi persecution among elderly Holocaust survivors Acta Psychiatrica Scandinavica 82, 311-315

Russell, C (1999) Interviewing vulnerable old people: Ethical and methodological implications of imagining our subjects Journal of Aging Studies 13, 4, 403-417

Seltzer, W & Anderson, M (2001) The dark side of numbers: The role of population data systems in human rights abuses Social Research 68, 2, 481-513

Shanan, J (1989) Surviving the survivors: Late personality development of Jewish Holocaust survivors International Journal of Mental Health 17, 42-71

Shavers, V.L et al (2000) Knowledge of the Tuskegee study and its impact on the willingness to participate in medical research studies Journal of the National Medical Association 92, 563-572

Shmotkin, D et al (2003) Tracing long-term effects of early trauma: A broad-scope view of Holocaust survivors in late life Journal of Consulting and Clinical Psychology 71, 2, 223-234

Silva, M.C (1995) Ethical Guidelines in the Conduct, Dissemination, and Implementation of Nursing Research Washington DC: American Nurses Publishing

Smith, L.J (2008) How ethical is ethical research? Recruiting marginalised, vulnerable groups into health services research Journal of Advanced Nursing 62, 2, 248-257

Spicker, P (2011) Ethical covert research Sociology 45, 1, 118-133

Sullivan, C.M & Cain, D (2004) Ethical and safety considerations when obtaining information from or about battered women for research purposes

Journal of Interpersonal Violence 19, 5, 603-618

Tilley, L & Woodthorpe, K (2011) Is it the end of anonymity research as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher Qualitative Research 11, 2, 197-212

White, R.M (2000) Unravelling the Tuskegee study of untreated syphilis Archives of Internal Medicine 160, 585-598

Wiles, R et al (2007) Informed consent and the research process: Following rules or striking balances? Sociological Research Online 12, 2 (http://www.socresonline.org.uk/12/2/wiles.html)

2. ALCOHOLISM AND THE YAMI

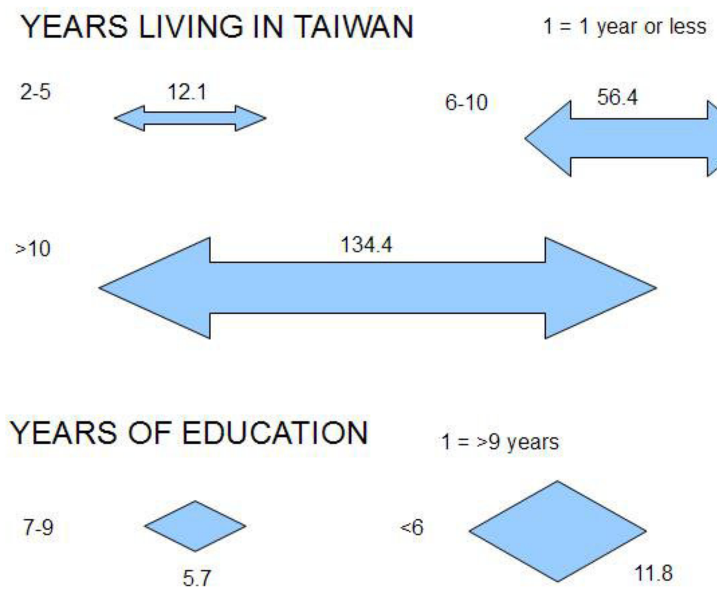
Among traditional agrarian indigenous groups around the world, alcohol consumption increases with modernisation and contact with industrialisation and consumerism. Alcohol consumption in these groups is traditionally limited and part of community bonding, whereas heavy drinking in response to modernisation is "frequently asocial and pathological" (Liu and Cheng 1998).

Liu and Cheng (1998) investigated alcohol misuse among the Yami people of Orchid Island, Taiwan (figure 2.1). Their society had been traditional up to the introduction of electricity in 1982 with limited contact with Taiwan. Alcohol, other than communion wine (as the Yami are mainly Christian), was introduced in the early 1980s in the form of imported cheap rice-wine. Alcohol is thus a symbol of modernisation.

Figure 2.1 - Location of Orchid Island.

Two random sample of Yami people aged fifteen years and above were interviewed about their alcohol consumption and behaviours covered by alcohol use disorders (AUD) (DSM-III-R and DSM-IV criteria) by experienced psychiatrists. In village 1 124 adults were questioned, and 113 in village 2.

The lifetime prevalence of alcohol abuse was found to be 11.8% (DSM-III-R criteria) and 9.9% (DSM-IV criteria), while alcohol dependence was 5.7% and 5.3% respectively [10] [11]. There were gender differences - eg: lifetime alcohol abuse (DSM-IV criteria) - 21.1% (men) and 2.7% (women). The key risks for AUDs in men were time living in Taiwan (>10 years), less education, and no religious beliefs (figure 2.2).



(Source: table p172 Liu and Cheng 1998)

Figure 2.2 - Odds ratio for lifetime AUDs among Yami men.

Hill (1978) has proposed three reasons (which are not mutually exclusive) for the increase in drinking with modernisation:

i) A response to social disorganisation caused by modernisation.

ii) A response to deprivation often experienced with modernisation (eg: movement from traditional lands to urban areas).

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[10] One-year prevalence rates for alcohol abuse were 7.4% (DSM-III-R criteria) and 5.0% (DSM-IV criteria), and 5.7% and 5.3% respectively for alcohol dependence.

[11] These figures were much lower than among four other aboriginal groups in Taiwan (45-50%) (Cheng and Chen 1995). This was up from 0.1% in the 1960s (Liu and Cheng 1998).

iii) As an attempt to maintain traditional values and social bonds.

Together all three reasons can explain the increasing alcohol consumption among the Yami people (Liu and Cheng 1998).

REFERENCES

Cheng, T.A & Chen, W.J (1995) Alcoholism among four aboriginal groups in Taiwan: High prevalence and their implications Alcoholism: Clinical and Experimental Research 19, 81-91

Hill, T.W (1978) Ethnohistory and alcohol studies Anthropological Research 34, 442-467

Liu, S-I & Cheng, A.T.A (1998) Alcohol use disorders among the Yami aborigines in Taiwan British Journal of Psychiatry 172, 168-174