

AP/SOSC 3116: 6.0 The Patient

Fall/Winter 2011-12

Course Project Handout: The Patient's Journey

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DESCRIPTION OF THE PROJECT:

This project challenges you to appreciate and analyze the journey of the patient. You are to do this by interviewing a patient and using the interview transcript as a 'text' to chart how they as patients experienced empowerment and the loss of power, how they imposed 'order' on the 'disorder' which illness visited upon their lives, how they understood, used, or discarded notions of the 'good' patient, and how their notions of self (i.e. body image, confidence, relationships with others) were reshaped by being ill. You should also analyze the patient's understanding of the cause and meaning of their illness.

Students should begin this project by finding a person who has had a significant illness experience and is willing to participate in their project. This can be a person who has experienced either a chronic condition or an acute illness. Please keep in mind that this person cannot be under the age of 16 or an incompetent adult. Remember that you cannot conduct your interview until your project proposal has been successfully reviewed by the course director. At this point you will receive a consent form which must be signed by your interview subject before you begin your interview.

PROJECT LEARNING OBJECTIVES:

- To develop a more nuanced understanding of 'the patient', informed by combining a personal connection with a patient with analysis gained through course material and their own secondary reading done specifically for this project.
- To plan and carry out a research project using data collected during field research and analysis and information gained through use of appropriate secondary sources.
- To understand and apply ethical research principles and practices.
- To locate, use and cite relevant scholarly secondary sources to support your own data.

ORGANIZATION OF THE PROJECT:

There are 3 parts to this project. Students must first complete **Part 1** of the project (proposal, interview schedule, preliminary bibliography, ethics statement) and hand it in. **Please note that you are not permitted to undertake your field research until Part 1 of your project is returned with a consent form. Students who do not follow this requirement will automatically receive a grade of zero.** Students go out into the field and do their interview as **Part 2** of the project. Students will then complete **Part 3** of the project, integrating comments, suggestions and additional secondary readings to set their findings in an analytical context and create project report.

PART 1: PROPOSAL, INTERVIEW QUESTIONS, PRELIMINARY BIBLIOGRAPHY & ETHICS STATEMENT – DUE 26th JANUARY

- Students must draw up a project proposal which includes the following: a statement of their objective(s) in the project, a description of the patient they are going to interview, and an explanation of why they have chosen this individual. Please note that the interview subject must remain anonymous.
- The proposal must include a list of 10-20 questions which the student intends to ask their interview subject in order to gain data to meet the objectives which they have outlined. Remember that open-ended questions that elicit a full answer rather than 'yes' or 'no' are best. Use phrases such as "Describe..." or "Tell me about..."
- Students must include a brief (5-10 articles or books – no websites please!) annotated bibliography of scholarly works which they intend to use in their analysis of the results of their project. This does not have to be a comprehensive, final bibliography. You are required to use the APA system of citation. An annotated bibliography is a full citation of the relevant book or article which is followed by a brief, 3-4 sentence description of the source listed. See attached sheets titled: "HOW TO FIND SECONDARY SOURCES" & "CORRECT SCHOLARLY CITATION."
- Students must read the Faculty of Arts Ethics website at: Students must read the Faculty of Liberal Arts and Professional Studies Ethics website at: <http://www.yorku.ca/secretariat/policies/document.php?document=94> (focus on Section 1: General Principles and 2 (a) Principles of Informed Consent and include a 100-word summary in their own words of their understanding of the ethical implications of interviewing people for research purposes.

PART 2: PROJECT INTERVIEW

- You should plan to spend approximately 40 minutes to 1 hour doing your interview. Interview questions should be based on an attitude of respect for the interview subject and appreciation for the time they have given to you.
- You must tell your interview subject who you are and that you are doing the interview as part of an assignment in a York University undergraduate course. You must also tell your interview subject that a pseudonym will be used instead of their real name in your project report. You are required to inform your interview subject that s/he has the right to terminate the interview at any time or to decline to answer any questions. You must go to your interview with an **Informed Consent Form** – which must be signed before the interview can begin. Remember that you need to give your interview subject time to read the form carefully.
- Please note that you are required to maintain all informed consent forms in a sealed container, securely in your possession for two years.

PART 3: PROJECT REPORT – DUE 8TH MARCH & WORTH 20% OF FINAL GRADE. NOTE THAT A COMPLETED SHEET WITH A 100% SCORE ON THE YORK UNIVERSITY LIBRARY ON-LINE ACADEMIC INTEGRITY AND PLAGIARISM TUTORIAL MUST BE STAPLED TO THE BACK OF YOUR PROJECT REPORT OR YOUR REPORT WILL NOT BE GRADED. THE PROJECT REPORT SHOULD DOUBLE-SPACED IN 12 POINT FONT, 2000-2500 WORDS IN LENGTH & ORGANIZED IN THE FOLLOWING FASHION:

- **Introduction & Objectives:** This section should set the subject of your research project in a broader context (for example - the ways in which patients can be analyzed, the nature of the illness suffered by your subject, and other ways in which you see your project fitting into the wider themes and topics covered in the course). This section should also contain a clear and detailed statement of your objectives.
- **Results & Analysis:** What were your findings? How did the interview respond to your questions? Use scholarly analysis to probe more deeply into your results. Does your interview data reflect issues and themes that arise in the scholarly literature – or does it take you beyond the literature? Do specific theoretical approaches or similar studies help you interpret your research? Be as creative and insightful as possible in this section. Remember to provide references for all ideas not your own. (This section should comprise the bulk of your project report.)

- **Conclusions:** What are the broad conclusions which you are able to draw from your project results and analysis? Do your conclusions contradict or support material covered in the course? Based on your conclusions, can you suggest future directions for research in this area?
- **Bibliography:** A complete list of interviews undertaken and of published secondary sources consulted for your report must be submitted. A complete list of interviews undertaken and of published secondary sources consulted for your report must be submitted. Remember that you must reference all ideas and information that is not your own. Please follow the APA system of citation (see attached pages.) A good bibliography will contain more than 8 citations which have clearly been used in the project report.

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HOW TO FIND SECONDARY SOURCES

1. Use the subject search on the York University library catalogue to locate material. Possible subject categories might include: Patient, Sick, Children, Pain, Chronic Illness or Chronically Ill, Care of the Sick, Mental Health or Mentally Ill, Intensive Care Nursing, Aging or Elderly or Geriatric Medicine, Nursing, Physicians, Professionalism or Profession, Hospitals, Alternative Medicine, Complementary and Alternative Medicine (CAM), Health and Poverty, Health and Race, Holistic Medicine, Health and Women, Indians and Health, Indian Women and Medical Care, Minority women and medical care, Healing, Transcultural medical care, Traditional medicine, Social Medicine, Family care, Spiritual healing, Health behaviour – cross-cultural studies, etc, etc, etc. I find that the “linked subjects” can be very useful in leading me to subject headings I might not have thought of otherwise.
2. Journal articles are of course another good source. Use the subject terms I have suggested above and others that you have found in your catalogue research. I recommend *Sociology of Health and Illness: A Journal of Medical Sociology; Health, Illness and Medicine; Medical Anthropology Quarterly; Social Science and Medicine; Ethnicity and Health, Complementary Health Practice Review* – York University has these online and possibly also on the library shelves. You can also find journal articles by using the library catalogue. From the homepage go into ERESOURCES, then ‘Find Articles by Subject.’ Then look under ‘Health’ and then ‘Sociological Abstracts.’ At that point you can search under a wide range of topics including: ‘patient and experience,’ etc. You may also wish to consult specific journals that work with your particular project, i.e. *Ageing and Society* is a wonderful journal about health and the elderly (note the UK spelling of ageing if you look for this one!)
3. When you find one good book, hunt around on the same shelf and nearby library shelves. If you find a good article in a journal, check out other volumes of the same journal. Look for other work by an author whose work you find useful or inspiring.
4. Remember that you are looking for literature about the human side of medicine and illness. Scientific literature may be useful for helping you understand the physical and medical parameters of an illness, but it will not help you to the journey of the patient you are interviewing. THIS IS REALLY IMPORTANT!!!
5. Remember to ask the reference librarians for help.

Good Luck!

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“CORRECT SCHOLARLY CITATION – APA SYSTEM”

To employ the analogy of building a house, footnotes and reference bibliographies are the wooden frames and main joists of a building – they tell the reader what ideas the author has drawn on to construct their arguments and analysis. If the reader sees that the author has used good scholarly sources (i.e. good building materials) then s/he knows that the work has scholarly integrity. If the author has used materials generated by people without scholarly credentials, or has failed to ground his/her writing within the relevant scholarship, then their writing is weakened by a lack of solid structure. Footnotes and endnotes also give credit to people whose ideas and data the author has used in preparing his/her analysis.

* PLEASE NOTE THAT THIS IS NOT A COMPLETE GUIDE TO APA CITATION & REFERENCE – IF YOU HAVE SOURCES TO CITE THAT ARE NOT DETAILED BELOW YOU WILL HAVE TO CONSULT AN APA-STYLE GUIDE.

1. APA IN-TEXT CITATIONS:**PARAPHRASE OR SUMMARY WITH THE AUTHOR’S NAME IN THE TEXT.**

Give the year of publication in parentheses after the author’s name.

Example: Howell (1997) believes that health status is determined by economic status.

PARAPHRASE OR SUMMARY WITHOUT THE AUTHOR’S NAME IN THE TEXT.

Give the author and year of publication in parentheses at the end of the cited material.

Example: The last decade has seen the rise of analysis which links health and economic status (Howell, 1997).

QUOTATION WITH AUTHOR’S NAME IN THE TEXT.

Give the year of publication in parentheses immediately after the author’s name, and put the page number at the end of the quotation.

Example: According to Howell (1997), “Health status and economic status are clearly linked” (p.3).

QUOTATION WITHOUT AUTHOR’S NAME IN THE TEXT.

Give the author, year of publication, and page number in parentheses at the end of the quotation.

Example: As has been stated by many researchers in the field, “Health status and economic status are clearly linked” (Howell, 1997, p.3).

A WORK WITH 2 AUTHORS.

List both authors’ names in the text with the year of publication immediately following, or put both names in a parenthetical citation. In this case, note that the ampersand (&) is used instead of *and*.

Example: The last decade has seen the rise of analysis which links health and economic status (Howell & Splot, 1999).

INTERVIEWS.

Identify that you are citing an interview and give date of interview.

Examples: Howell and Splot (interview, June 2, 1999) believe that their study demonstrates a clear link between gender, health and economic status. OR: The researchers believe that their study demonstrates a clear link between gender, health and economic status (interview, Howell & Splot, June 2, 1999).

2. APA-STYLE REFERENCES:

In APA style, the alphabetical list of works cited that appears at the end of a research paper is called *References*. Follow these basic guidelines:

1. Reverse *all* authors' names within each entry, and use initials, not first names.
2. Name *all* authors.
3. Give the date of publication in parentheses after the last author's name followed by a period.
4. Put the title of the book, journal or website in *italics*.
5. Indent the first line of your reference (see examples below).
6. In the case of a journal article list volume, number and page numbers after the journal title (see example below).

BASIC FORMAT FOR A BOOK WITH ONE AUTHOR.

Howell, Z. (1997). *Class and health*. Toronto: University of Toronto Press.

BOOK WITH 2 OR MORE AUTHORS.

Howell, Z. & Splot, A. (1999). *Gender and health*. Vancouver: UBC Press, 1999.

ARTICLE IN JOURNAL.

Splott, A.(2003). Single women, poverty and health: analysis of data from the Romanow Report. *Canadian Journal of Women's Studies*, 20, 4/4, 16-33.

INTERNET.

Howell, Z. (2000). Poverty and health? In *Health in action website*. Website: <http://www.uottawa.ca/healthinaction>. Retrieved 25 February 2009.)