



**A SOCIAL WORK GUIDE
TO
CONDUCTING RESEARCH
IN
PSYCHOSOCIAL
ONCOLOGY**

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I: INTRODUCTION

As oncology social workers we are committed to the goal of evidence-based practice with cancer patients, survivors and their families. We need empirical support, or data collected with scientific methods, to confirm our clinical perceptions and to establish which social work interventions are most effective with a given population.

Although social workers are making significant contributions to the body of knowledge about cancer survivors (Blanchard, Toseland & McCallion, 1996; Roberts, Cox, Reintgen, Gibertini & Baile, 1994; Zabora et al, 1997; Zebrack & Chesler, 2001), many important research questions remain unanswered. We believe that social work clinicians, who provide the major share of psychosocial support and mental health care to cancer patients and their caregivers, should be actively involved in psychosocial oncology research. Presentation and publication of our findings will lead to personal and professional recognition as researchers on the interdisciplinary team at our institutions as well as at the national and international level.

Most oncology social workers would agree with this position but also feel they lack the skills, experience or time to integrate research into their practice. The purpose of this Research Guide is to provide a basic set of research tools to enable clinicians to venture into the sometimes mystical world of research. Clearly, this monograph will not provide the depth of training needed to conduct complex research. However, clinicians and students in early stages of research training may find it helpful. We will provide an overview of the research process with resources for you to consult for more in depth information. Additionally, we have included some "insider tips" on topics such as how to do a literature review, where to find instruments for data collection, and how to get your findings disseminated to the people who will benefit from them. Our ultimate goals are to get you both interested and enthusiastic about doing research, provide the necessary information to get you started, and to build confidence in your ability to complete a research study either independently or collaboratively.

If you are a member of AOSW when you decide to launch a research study, we encourage you to join the Social Work Oncology Research Group (SWORG), a committee within the Association of Oncology Social

Work. Contact the SWORG Chairperson, listed on the AOSW website, who will arrange for you to be put on the SWORG listserve. This group provides networking opportunities as well as information and advice on conducting research studies. If you are not a member of AOSW we welcome you to join. Please visit our website for information at www.aosw.org.

II: AN OVERVIEW OF TYPES OF RESEARCH

It is useful to categorize types of research studies to help you conceptualize your research. Some textbooks categorize studies according to levels of research or to the purposes of research (Rubin & Babbie, 2001). Regardless of the terminology, there are four approaches to research relevant for social work researchers. Some research projects might include more than one type of approach.

The four types of research are:

Exploratory: This type of study addresses a new phenomenon or applies when there are relatively few studies on a topic. Exploratory studies generally use qualitative research techniques, (see section VI). The nature of the inquiry is open and intuitive as there are no pre-existing hypotheses to test and the theory emerges from the research, rather than being preconceived. An example is a study of a successful support group, for instance, to learn what really happens between the members of the group.

Descriptive: The purpose of this type of study is to answer questions such as how many, how much, or how often. For example, Krizek, Roberts, Lord, Ferrara, and Ragan (1999), described how many prostate and breast cancer patients had ever attended a support group and their reasons for attending. Descriptive statistics are used to report averages, ranges of responses, frequencies and percentages.

Correlational: A study of this type examines associations between variables. For example, Roberts, Rosetti, Cone and Cavanagh (1992) investigated the relationship between age and psychological distress among women who had radical surgery for gynecological cancers. The use of inferential statistics, such as the Pearson Product-Moment Correlation coefficient, Student's t-test, and Chi Square test for statistical significance, determine if

apparent associations among variables are more than just chance occurrences.

Explanatory, or Cause and Effect: In this type of study, an attempt is made to test a hypothesis or a suggestion that one variable "causes" or precedes another. For example, an explanatory approach is used to investigate whether participation in a weekly Internet chat room discussion reduces patient distress. Explanatory investigations are the most sophisticated type of research and often require more experimental control and statistical manipulation.

III: DEVELOPING A RESEARCH TOPIC

Research topics or questions can arise from your clinical practice or personal observations. Some possible questions are:

- *What is the quality of life of long-term survivors of adult leukemias and lymphomas? (See Zebrack, 2000.)*
- *Do cancer patients who attend your support group for young adults benefit from it? (See Roberts, Piper, Denny & Cuddeback, 1997.)*
- *Do patients who use complementary and alternative medicine have a higher health locus of control? (Study underway in collaboration between the American Cancer Society and SWORG: Use of Complementary Therapies among Breast and Prostate Patients.)*
- *Do patients want their doctors' recommendations to assist in making treatment decisions? (See Johnson, Roberts, Cox, Reintgen, Parsons & Levine, 1996).*

These examples represent **empirical questions**. An empirical question is one that can be answered through **research**. **Research** is a purposeful and systematic method of observation that involves the collection and analysis of information (data) that answers a question. A purposeful and systematic approach to answering a question involves the following:

- Clearly defining your research question. (To be covered in the remainder of this section)

- Learning what research has been done and what is already known about a patient population or issue. In Section IV, we will discuss how to review the literature to guide you in developing your study.
- Selecting the best research design to answer your question. Research designs fall into one of four categories as presented in Section II.
- Selecting the best research methods and procedures. Research methods commonly used by oncology social work researchers are presented in Sections V-VI.
- Learning procedures for protection of human subjects, (i.e. informed consent, voluntary participation, and confidentiality) in accordance with the Social Work Code of Ethics and Institutional Review Board requirements, is yet another important component of research. This topic is covered in Section VII.
- Lastly, upon completion of your study, you must decide how, where, and with whom you share your newfound information and knowledge. Section IX addresses methods of dissemination for research findings.

Now that we have provided an overview of the research process, let us discuss the first step of developing the research topic or question.

Defining a research question and justifying its relevance

First, **conceptualize** your question. In the above example regarding the support group for young adults, we must consider three concepts: (1) what is the nature and purpose of the support group; (2) what do we mean by "young adults;" and (3) how might we evaluate or measure the concept of "enhanced adjustment." Regarding long-term survivors of adult leukemia and lymphoma, Zebrack (2000) conceptualized quality of life broadly to include positive as well as negative outcomes in physical, psychological, social, and spiritual/existential dimensions.

In the research question about use of complementary therapies, we must think through the concept of

"complementary therapies" as well as that of "locus of control". We must define and distinguish "complementary therapies" from conventional ones, as well as define the types of therapies we are interested in evaluating (i.e., massage, visualization, biofeedback, etc.). As for locus of control, it is important to define the term and place it in its psychological and theoretical origins.

Second, given your ponderings, as well as your review of the literature, you create some **hypotheses** or clearly stated **research questions**. Roberts, Piper, Denny, and Cuddeback (1997) hypothesized that young adults attending a support group designed for their age group would experience improvement in their emotional well-being. Zebrack (2000) posed the question "To what extent is quality of life of long term survivors a function of current age or life stage, or age at diagnosis?" In the complementary therapies study currently in progress (mentioned above), it is hypothesized that patients who believe their health status is determined by their own behavior (internal health locus of control) will be more likely to use complementary therapies than those who believe their health status is determined by chance or some force outside of themselves.

Third, **operationalize** your terms. This means being as specific as possible so that your methods of answering your question will relate as precisely as possible to your question. For instance, how will you measure "response" to participation in a new group or to a new method of clinical assessment? You may actually be interested in an increase in knowledge about cancer and/or treatment, or you may be interested in a change in participants' emotional well being. These are examples of two "responses."

Operationalizing your terms refines your hypothesis, and enables you to locate existing instruments that were designed to measure the concept of interest to you. For example, there are many quality of life instruments available from which Zebrack (2000) selected the *Quality of Life-Cancer Survivors Scale* because it assesses multiple dimensions of quality of life specific to a population of cancer survivors. In some instances, you may need to develop your own questions in order to assess or collect data on the concept of interest. In addition to administering an existing measure of quality of life, Zebrack (2000), also conducted structured face-to-face interviews

asking survivors to discuss ways in which "having had cancer affects their life."

Finally, it is important to address the **significance** of your research question, to justify its **relevance**. By addressing the following questions, you will be providing a justification for developing an approach that attempts to answer your concerns. *What is the significance of your question? By answering your question, what will you achieve? Will the knowledge you gain guide or inform evidence-based practice?* It is important to ask yourself these questions to help you decide whether you wish to pursue this research topic. In addition, if you wish to get your study published, the journal editors who review it will most certainly want you to discuss the implications of your study for social work practice. Finally, persons you may ask to sponsor or support your research will expect you to be able to speak to its significance.

IV: REVIEWING THE LITERATURE

An important step in conducting research is investigating what others have published on the same topic by doing a literature review. This step is important for several reasons: (1) it helps determine the feasibility of your planned project, (2) it helps you to become an expert on the topic, (3) it assists you in selecting measurement tools or instruments, and (4) it identifies conceptual and practical obstacles encountered by other researchers. The literature review process can be time consuming but is well worth the time spent.

Why Do a Literature Review?

1. To help you focus on a topic to research.
2. To acquire an understanding of the topic and state-of-the-art developments.
3. To underscore the significance of the problem and why the research is needed.
4. To decide what line of research can best build on the work already done.
5. To know whether the research question has already been adequately answered.
6. To identify alternative conceptions of the problem and the variables.
7. To identify variables relevant to the topic and how they have been *conceptually* defined in the past.

8. To determine how variables have been *operationally* defined or measured in the past. In other words, to learn what instruments have been or are being used by others in the field.
9. To learn what research methods have been used to evaluate similar research questions and hypotheses.
10. To understand the links between theory and practice.
11. To identify problems encountered by others and determine how to overcome those obstacles before you start.

Where Do You Start?

There are a number of steps in this process, which begins with locating relevant journal articles and ends with a written review of the findings in previous studies. A good resource that describes the process is *Doing a Literature Review: Releasing the Social Science Research Imagination* (Hart, 1998).

To begin, talk to colleagues to learn whether they have any articles on your topic of interest. This step helps in narrowing your focus and in developing a list of keywords that you will use during your computer searches. Look at the reference lists from articles you and your colleagues have assembled to identify relevant articles and authors. Next go to your local public library, college or university library, or a medical library. Talk to the resource librarians: they are highly trained and able to assist in your search. They will likely guide you to computerized indices and databases.

Computerized Indices and Databases

As a guideline, it is a mistake to assume that everything ever printed is already on the World Wide Web, available for free merely by typing in a few keywords in a search engine such as Google, Yahoo, Alta-Vista, Northern Light, and others. In fact, that is the last place to begin a serious literature review.

However, there are hundreds, if not thousands, of databases available. Typically, these may be found via the World Wide Web that provides electronic versions of journal abstracts, or even entire articles, available for a fee. Most colleges and universities will have these available. The universities are already paying a fee and provide them as a resource to

students, faculty and staff. If you have a login ID, in all likelihood you have access.

Among the more relevant databases for computerized literature review searches for social work research are:

- **Social Work Abstracts.** This database is produced and maintained by the National Association of Social Workers, Inc. It contains more than 35,000 records where each record represents an abstract of one article, spanning 1977 to the present, from social work and other related journals on topics such as homelessness, AIDS, child and family welfare, aging, substance abuse, legislation, community organization, and more.
- **PsychINFO.** This database indexes over 1300 journals in psychology and related disciplines.
- **Periodical Abstracts (via UMI's ProQuest Direct).** This database provides multi-subject references covering general and academic periodicals. An added bonus is that full-text is available for many articles.
- **FactSearch (Statistics).** This database is a guide to statistical statements on current social, economic, political, environmental and health issues. It is derived from newspapers, periodicals, newsletters and documents such as the Congressional Record, Congressional hearings, Daily Press Briefings of the White House, State Department and Department of Defense, and Australian, British and Canadian Parliamentary Debates.
- **Journals@Ovid.** This database includes the full text of selected journals in nursing and psychology, as well as citations from a variety of other journals.
- **Health and Psychosocial Instruments.** This database provides ready access to information on measurement instruments (i.e., questionnaires, interview schedules, checklists, index measures, coding schemes/manuals, rating scales, projective techniques, vignettes/scenarios, tests) in the health fields, psychosocial sciences, organizational behavior, and library and information science.

- **Medline/PubMed**, a service of the National Library of Medicine, provides access to over 12 million MEDLINE and additional life science journals citations back to the mid-1960's. PubMed includes links to many sites providing full text articles and other related resources. It can be accessed at <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>.

How Do You Search the Literature?

The best way to prepare for a literature search is to develop a list of key words that you will use in searching the databases. An example of a topic one might be interested in is "Coping and Cancer". Coping is a broad topic so you need to narrow it down to the type of coping you are interested in. Using "coping with cancer" as the keyword phrase in **Social Work Abstracts** resulted in 46 abstracts with the following types of coping: coping style; coping methods; coping skills; coping with the diagnosis; family coping; coping resources; coping strategies; coping capacities; and coping patterns.

Using the same keyword phrase in **PsychINFO** netted 150 abstracts. Examples of some of the topics were: self-efficacy for coping; spiritual coping; coping as reality construction. This suggests a need to narrow down what type of coping you are interested in so the literature will be more on target with your specific interest.

Plan to search the literature by looking at a time frame of the past five years; if you don't find much go back ten years. The only reason to go beyond ten years is for classic studies or seminal work. An example of this is Weisman and Worden (1976-1977), "The existential plight in cancer: Significance of the first 100 days".

With your keyword list in hand, conduct several searches on a number of the databases and read the abstracts. By reading the abstracts and selecting ones that seem appropriate, you will develop a list of articles that you want to read completely. Some of these articles will be available online while others will require going to the library stacks and making a copy from the journal.

When Do You Have Enough Literature?

You have enough literature on the topic when you keep getting the same references every time you go to the library. You also have enough literature when the list of articles you have collected are the same ones cited in the literature on similar research topics. Another clue that you may be done collecting literature is that instead of reading the articles you have collected and starting to write a review, you keep searching for more articles!

What is a Quality Literature Review?

Quality in a literature review means "appropriate breadth and depth, rigor and consistency, clarity and brevity, and effective analysis and synthesis; in other words, the use of ideas in the literature to justify the particular approach to the topic, the selection of methods, and demonstration that this research contributes something new" (Hart, 1998, p. 1).

Analysis of the literature is the process of systematically breaking down the topic into all of its parts and presenting the manner in which they are related. Synthesis of the literature is making connections between the parts identified in the analysis. This is a process of reconfiguring all the information into a new or different understanding of the topic or problem (Hart, 1998). It is important to give credit to those who helped you come up with this new understanding - the authors of the articles you analyzed and synthesized. The most common style in the social sciences is APA style. To learn more about APA style you can purchase *Publication Manual of the American Psychological Association: Fifth Edition* (2002). Other resources about APA style that can be found on the web can be found directly following the Reference list.

How Do You Organize Your Literature?

Once you have read the articles, you need to organize them to facilitate writing the review. One way is to organize the articles by variable, then focus on one variable at a time and summarize what the literature taught you. Then reorganize the articles into two groups: one set of articles that supports your own observations or ideas, and one that does

not. Summarize these articles. It is important to include literature that does not support your hypothesis to show that you looked at all angles of the topic or problem. Reorganize the articles again in a sequence, usually chronologically. This will allow you to write about the ways in which the research on a topic or problem has changed over time. You might wish to assemble articles using methods and instruments that you could adopt. Or you may group the articles into those that address theory and those that focus on clinical practice. This will help in organizing your synthesis of previous research.

Here is an example of organizing your literature review articles.

Topic: Depression and Cancer

- Step 1:** Collect articles within the past five to ten years that address depression and cancer. Read the articles and develop a list of variables identified as related to depression and cancer.
- Step 2:** Organize your articles by the list of variables (age, gender, cancer site, marital status, etc). Write a summary of the articles about each variable.
- Step 3:** Organize the articles by those that support your hypothesis and those that do not support it. Write up a summary of these groups.
- Step 4:** Organize the articles chronologically. Write up a summary of how the understanding of depression and cancer has changed over time.

Now all you need to do is write this up in a clear coherent review of what you have learned. Remember that one of the goals is to teach your readers about your topic or problem as well as provide support for your research question or hypothesis.

Consider Writing a “Review of the Literature” Article

We have discussed reviewing the literature as a preliminary step in your research project. However, many journals publish comprehensive and timely “review articles” which you may come across in your literature search. You may perhaps want to submit your review as a manuscript. After you have completed your research study and are ready to

submit the final manuscript, you can use a shorter version of the review, if indeed your comprehensive review was accepted for publication.

V. QUANTITATIVE RESEARCH METHODS IN ONCOLOGY SOCIAL WORK

Oncology social workers may use either quantitative or qualitative research methods.

The question about whether to use quantitative or qualitative research methods has to do with the type of research question you are asking. If your research begins with a hypothesis, uses formal, standardized instruments, and samples a large number of people with the goal of generalizing to the population, then the method of research would be quantitative. If your research begins with a question which is expected to change as you gather information overtime, uses primarily semi-structured interviews and observation, and samples a small, purposive group to uncover and understand what lies behind a phenomenon about which little is known, the method of research would be qualitative. In general, quantitative studies use numbers to describe their findings, and qualitative studies analyze words and images. Both methods contribute to our knowledge base, in different but complementary ways. Both require completing IRB process as outlined in Section VII of this manual.

Much of the social work knowledge base has been derived from qualitative approaches as they are in close accord with our clinical skills of observation, interviewing and assessment. However, much of the research in psychosocial oncology has used quantitative approaches, which are described in this section. Qualitative methods are then presented in Section VI. We hope that this information will help you select the research methods that fit you and your area of inquiry. You may also decide to use both methods in a mixed-methods study.

A: SURVEY RESEARCH

In a fine guide for survey research, Fink (2003) suggests that conducting a good survey involves

- setting objectives for information collection (see Section III, Developing a Research Topic)
- designing the study
- preparing a survey instrument
- administering the survey
- managing and analyzing survey data (see Section VI, A Mini-Course in Statistics)
- reporting the results (see Section X, Disseminating Research Findings)

Designing a Study

The design format you select will depend upon the information you seek and the objectives of your study.

Surveys are most often used in one of two design formats. The first format is **descriptive or observational**, where your intent is to understand the characteristics of a group, a program, or other phenomenon. In descriptive or observational studies, data are collected at a certain point in time (**cross-sectional**), offering a slice of life or snapshot description of a group of people, an activity, or an environment. Data also may be collected at numerous points in time (in the past or the future) from or about a **cohort** - a population that shares a certain set of characteristics. A **cohort design** is useful if your intent is to see if knowledge, attitudes or behaviors within a defined group of people change or changed over time. In some instances you may use a **case-control** design if you want to compare a population of interest (cancer patients) with at least one other (people who have not had cancer).

A second design format is **experimental**, where your intent is to examine how a certain set of experiences (such as death of a parent, breast reconstruction, bone marrow transplant) imposed on a group does or does not create change in that group. Experimental designs are useful to establish the effectiveness of an intervention (such as individual or group counseling) in a particular group of people. To read more about experimental designs in intervention research, see Part C of Section V.

Sampling

Designing a good study also involves attention to recruiting appropriate subjects and how you select them. Once you have defined a target population of interest (e.g., caregivers of elderly breast cancer patients), determining **eligibility criteria** and a **sampling method** will help you focus on creating a sample that is most representative of the population. Determining **eligibility criteria** involves selecting characteristics that all subjects in your sample must have as well as characteristics of people who will not be included in the study.

Example:	A study of caregivers of "elderly" (over age 80) patients
Inclusion criteria:	Married spouses, partners living as married, siblings.
Exclusion criteria:	Caregivers who do not reside with the patient, non-English speaking

Once you have determined who will be included in your study, you must decide how you will recruit them. A **simple random sample** assures that every subject in your population has an equal chance of being selected and increases the likelihood that your sample is representative of the target population. If your target population is patients receiving a particular treatment protocol, one way of selecting a simple random sample is to take an unalphabetized, computer-generated list of names and selecting every n^{th} name until you reach a desired number of subjects.

Non-probability samples do not guarantee that all eligible persons have an equal chance of being included in your sample, thereby limiting your ability to generalize your findings to a larger population. A common form of non-probability sampling is **convenience sampling** in which a willing and available group of individuals are recruited for participation. Using this approach, respondents may be recruited from newspaper advertisements or flyers posted in waiting rooms, asking potential subjects to call you to volunteer to answer your survey. This approach is convenient, economical and often appropriate for use in many surveys.

Preparing a survey instrument

Once you have determined an appropriate study design, you will need to consider how best to collect, or **survey**, information. Three common forms of surveys are **self-administered questionnaires**, **telephone or face-to-face interviews**, or **structured record reviews**.

Self-administered questionnaires are most often administered through the mail, and more recently via the Internet. This approach permits large-scale collection of information in a cost-effective manner and maintains privacy and anonymity for the individual completing the survey. Being alone while answering the questions can increase the possibility that a respondent will provide honest answers, particularly to personal questions.

Telephone and face-to-face interviews involve the subject interacting with an interviewer. This approach can be structured so that the interviewer follows a protocol, or script, to assure that every interview is conducted in the same manner. Using multiple interviewers requires training so that each interviewer performs the interview in a standard fashion and decreases the likelihood of introducing bias. Involvement of an interviewer can also assure that the respondent completes the entire survey. However, a face-to-face interview may increase the possibility that respondents will be concerned about presenting themselves in a favorable light to the interviewer and consequently be less than frank.

Structured record reviews permit examination of written, oral and visual records. For instance, obtaining information from medical records may provide the information necessary for an investigator to answer a particular question about patients' health status.

Questions and Answers

Creating and formatting your survey involves making some decisions about the types of questions you will ask of your information sources. You may include pre-existing instruments and measures, or your research question and intent may necessitate creation of your own questions.

Types of questions

Closed-ended questions most often are used in surveys and require respondents to select predetermined answers to questions. In answering, respondents select a category (*yes/no; true/false; male/female; income level*), indicate a range of agreement or importance (*strongly agree to strongly disagree; most important to least important*), or determine a frequency (*not at all to a lot; never to always*).

Open-ended questions permit respondents to answer in their own words, which allows for rich and in-depth answers to questions. These types of questions are useful when not a lot is known about an issue and when using predetermined response categories may limit the information that respondents could provide.

In selecting appropriate questions, here are some important considerations:

Avoid conditions, such as high reading level, poorly written questions, stressful environment, that can make it difficult for respondents to properly understand or interpret directions or questions (**Reliability**)

Assure that your survey questions are true and accurate measures of your overall research question and directly relate to your topic (**Validity**)

Assure that questions are meaningful and comprehensible across different ethnic/cultural groups (**Culturally appropriate**)

Take into account the energy level of your subjects, their ability to remain focused over a particular period of time, and the time necessary to complete the survey (**Respondent burden**)

Avoid leading questions (**Bias**)

Pilot testing

Before conducting a full survey, first pilot test your questions with several persons who are similar to the people who will eventually be your research subjects. Ask test subjects if the reading level is understandable and the questions comprehensible and culturally appropriate (**reliability**). Ask respondents what they think the overall purpose of the study is, based on your questions (**validity**). Monitor how long it takes for subjects to complete the questions and ask what difficulties they encountered.

Administering the Survey

A basic method for **self-administered** surveys is the transmission of your questionnaire, along with a letter of explanation and a self-addressed, stamped envelope for returning the questionnaire. In some cases your Institutional Review Board (see Section VII) may require you to first send a letter of invitation and a response form to potential participants, requesting their consent to receive your survey. Your procedures can also include follow-up telephone calls to inquire whether respondents received the questionnaire and if they have any questions about completing it. Two to three weeks following the first mailing is recommended as an adequate waiting period before either calling or sending a second questionnaire.

Careful monitoring of your mailings should involve records of the date mailings were sent and the date completed surveys were received, date and time of follow-up telephone calls, and date of second (or third) follow-up mailings. It also is important to keep track of surveys returned by the post office and marked "non-deliverable" or "no forwarding address." Current phone books and the Internet are helpful resources for locating recent addresses for some of your undeliverable mailings.

Telephone and face-to-face interviews require somewhat different procedures. Typically, you will mail a letter to eligible subjects informing them of the study and inviting their participation. A telephone contact to potential subjects will determine if they wish to participate, possibly followed by obtaining written verification of their informed consent. You then schedule a time that is convenient for the subject, and if interviewing in person, a place is arranged. For a review of important details and aspects of conducting successful surveys via mail, face-to-face, or telephone, see Singleton and Straits (2002) chapter on Survey Interviewing.

B. RESEARCH INSTRUMENTS

Selecting A Standardized Instrument

Identifying the instrument or measurement tool you plan to use to collect data for your study can at times seem intimidating. Every researcher has his/her favorite instrument and a very good argument for why

one should use that instrument. This does not mean that you cannot vary from what others have used. When deciding what instrument you are going to use, you need to first decide whether you are going to use a standardized instrument or an investigator-developed instrument.

A standardized instrument (e.g., tool, survey, test, questionnaire, measurement and the like) is one that has uniformity of procedures for administering and scoring. It may also provide norms for comparison. A standardized instrument also makes available existing data concerning the reliability and validity of the measure. Reliability refers to the consistency or stability of the instrument, or the degree to which a variable has nearly the same value when measured several times. Validity refers to how well the instrument measures what you want it to measure, or the degree to which a variable actually represents what is it supposed to represent. An investigator-developed instrument is one that you design, for example, when you cannot find a standardized instrument that measures what you plan to measure.

This section will focus on selecting standardized instruments. As discussed in Section IV, a review of the literature will help you identify the instruments that have been used in the past to measure the variables you are interested in. Also, this review will reveal the instruments effectiveness in answering research questions and hypotheses.

Table 1 provides some guidelines for picking an instrument.

Whatever measurement tool or instrument you choose to use in a study or in your practice, it is important to learn whether you need to get permission from the authors or owners of the copyright, or whether it is necessary to purchase a license for use. In some cases, the authors and/or owners of the copyright for that measurement tool only need to be asked and will give permission for use at no cost. Others will expect you to pay for use of the instruments. The prices vary based on the exact measurement tool, on the number you will use, and occasionally on the purpose of your study.

Table 2 presents a sample of standardized instruments used in psychosocial oncology research to measure different variables of interest. This is not an exhaustive list of instruments and does not imply that any

Table 1: Guidelines for selecting an instrument

Guideline	Comment
Purpose	<ul style="list-style-type: none"> • What kind of variables or concepts is the instrument designed to identify? • What clients has it been used with? • Is it suitable for your population?
Directness	<ul style="list-style-type: none"> • To what extent does the instrument directly measure the variable or concept? (A more direct instrument is more likely to register any changes that occur.)
Relevance to intervention planning or research question	<ul style="list-style-type: none"> • How does the instrument relate to your intervention? • Does it identify clients who need intervention? • Will the instrument show whether the intervention is effective?
Reliability	<ul style="list-style-type: none"> • Does the instrument measure effects consistently over time?
Validity	<ul style="list-style-type: none"> • Does the instrument measure what you mean to measure?
Ease of use	<ul style="list-style-type: none"> • How much time does it take to administer the instrument? • How much time does it take to score? • What reading level does the instrument require in order to be understood by the respondents?
Accessibility	<ul style="list-style-type: none"> • Copyright issues • Cost • Training in administering and scoring
Multidimensional	<ul style="list-style-type: none"> • Measure more than one dimension of the concept (subscales)

instrument on this list is better than one that is not on the list. This list was developed from what has been used in the literature.

The Table (pages 11-13) columns are as follows:

Title of Measure: The full title of the measurement tool and its abbreviation.

What It Measures: What concepts the measurement tool has been shown to measure.

Format of Measure: The format of the measure including:

- The number of questions
- The response set
- The possible ways of scoring available

Who and How Long: This includes information on:

- Characteristics of persons on whom the measurement tool has been tested
- The reading level reported necessary
- How long it takes (on average) to complete

How To Obtain Measure and Information on

Translations: This contains:

- The web site or address and phone number of source of measurement tool

- The languages that the measurement tool has been translated into

Other resources for finding measurement tools are from the literature, which is discussed in Section IV. There are also books published that present various measurement tools by population and concept to be measured. One example of this is *Measures for Clinical Practice: A Sourcebook* by Corcoran and Fisher (2000). Volume 1 includes a wide range of standardized instruments for couples, families, and children, and Volume 2 provides standardized instruments for adults. Corcoran and Fisher provide the following information for each instrument included in their book:

- What the instrument measures
- Reliability and validity information
- The population(s) the instrument has been tested on
- Scoring information and how to interpret results
- Where to obtain copyright information

Title of Measure	What It Measures	Format of Measure	Who and How Long	How to Obtain Measure and Information on Translations.
Brief Symptom Inventory-18 (BSI-18) (Derogatis, 2000; Zabora et al, 2001)	Psychological Distress – Depression, Anxiety, Somatization	18 item 5-point Likert scale. Hand score or MICROTTEST Q™ software scoring. Raw scores can be used to determine level of distress.	18 years and older 6th grade reading level, about 4 minutes to complete.	http://assessments.ncspearson.com Must meet qualification requirements and purchase BSI-18 Manual and Answer sheets. Available in English and Spanish).
Brief Symptom Inventory (BSI) (Derogatis, 1993)	Psychological Distress - 9 subscales including Depression, Anxiety, Hostility and 3 global scales including Global Severity Index	53 item 5 point Likert scale, Hand score, on-line, audiocassette, or MICROTTEST Q(tm) software used to score. Normalized t scores used and compared to norms.	13 years and older, 6th grade reading level, about 10 minutes to complete	http://assessments.ncspearson.com Must meet qualification requirements and purchase BSI-18 manual and Answer sheets. Available in English, Spanish, French for Canada and Large Print.
SF-36 Health Survey SF-12 Health Survey SF-8 Health Survey (Ware & Kosinski, 2001)	Health Survey representing 8 operational indicators of health with physical and mental health summaries	36, 12 or 8 items based on version. Variable response set depending on the question. Standard and Acute Forms, algorithm available or online scoring service available.	Individuals 18 years and older. Norms available by gender, age and chronic illness.	Purchase manuals from Quality Metric, Inc. at www.qualitymetric.com , various types of licenses available. Available in many languages.
Center for Epidemiological Studies Depression (CES-D) (Hann, Winter & Jacobson, 1999)	To detect major or clinical depression	20 item 4-point response set. Reverse code and hand score, norms provided.	Adolescents and adults. Approximately 10 minutes.	Available for on-line scoring at www.assessments.com or /www.wpic.pitt.edu/research (this is only two of many). To download paper version, go to www.chcr.brown.edu/pcoc/cesdscale.pdf (one example).
The Functional Living Index - Cancer (FLIC) (Schipper, Clinch, McMurray, & Levitt, 1984)	A measure to estimate the quality of life of patients with cancer	22 item 7-point scale, actual response set different for each questions.	Less than 10 minutes.	Contact Harvey Schipper, M.D. World Health Organization, Collaborating Centre for Quality of Life in Cancer Care, St. Boniface General Hospital Research Centre 351 Tache Avenue, Winnipeg, Manitoba, Canada R2H 2A6 Fax: (204) 235-1231

Title of Measure	What It Measures	Format of Measure	Who and How Long	How to Obtain Measure and Information on Translations.
Functional Assessment of Cancer Therapy (FACT-G) Version 4. (Cella et al., 1993; Cella, 1997, 1998)	Questions divided into four primary QOL domains: Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being	27-Item 5-Point Likert scale. Scoring programs for SAS and SPSS available.	6th grade reading level. Estimated time for completion: 5 min.	All collaborators must complete a Collaborators' Project Information Form prior to the use of any FACT-G scale at www.facit.org . The manual is available to collaborators for a fee as well as the scoring diskette. Available in 38 languages
The Family Adaptability and Cohesion Scales II (FACES II) (Olson, Portner, Lavee, 1988) The Family Adaptability and Cohesion Scales III (FACES III) (Olson, 1986)	Assesses two major dimensions: family cohesion and family adaptability (flexibility). It is designed to be administered to families across the life cycle.	FACES II is a 30-item self-report instrument. FACES III is a 20-item self-report instrument. Hand scored.	Adolescents and adults.	Please note that if you are planning to use FACES for any kind of research that FACES II is recommended over FACES III. FACES II has better reliability and validity. FACES III is recommended for clinical work because it is shorter in length. Order from www.lifeinnovations.com .
Family Environment Scale (FES) (Moos & Moos, 1986)	measure social and environmental characteristics of families	90 item with true or false response sent. Grouped into 10 subscales within three dimensions: Relationship, Personal Growth and System Maintenance.	Adolescent and adult. 10 to 15 minutes, 6th grade reading level	Can be obtained from MindGarden www.mindgarden.com . Translated into Spanish, Korean, and Chinese.
Dyadic Adjustment Scale (DAS) (Spanier, 1976)	Measure of relationship adjustment.	32 item, different response set per section.	Adults, Literate 5-10 minutes, hand scoring or software scoring.	Can be obtained from MHS Inc., P.O. Box 950, North Tonawanda, NY 14120-0950 www.mhs.com TEL: 1-800-456-3003 FAX: (416) 492-3343 or (888) 540-4484 Price discount if DAS used in research.

Title of Measure	What It Measures	Format of Measure	Who and How Long	How to Obtain Measure and Information on Translations.
<p>Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin & Thompson, 1991)</p>	<p>To identify problem-solving and behavioral strategies utilized by families in difficult or problematic situations.</p>	<p>30 Likert-scale items</p>	<p>Adolescents and adults</p>	<p>Family Stress, Coping and Health Project 608-262-5070 To use this instrument you must get written permission by paying a one time copyright small fee.</p>
<p>The Spiritual Well-Being Scale is a general indicator, which may be used for the assessment of individual spiritual well-being.</p>	<p>Spiritual Well-Being Scale (SWBS) (Bufford, Paloutzian, & Ellison, 1991)</p>	<p>20 items, ten of which assess religious well-being specifically, and ten of which assess existential well-being.</p>	<p>10-15 minutes, adults</p>	<p>Can be ordered directly through Life Advance, Inc., in small or large quantities at www.lifeadvance.com/products.htm. Available in Spanish</p>
<p>European Organization for the Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993)</p>	<p>Assess the following quality of life areas: general physical symptoms, physical functioning, fatigue/ malaise, social and emotional functioning, and overall quality of life.</p>	<p>30 items, most rated on a 4-point Likert scale, others yes/no format. The global QOL items are in a 0-6 visual-analog superimposed. All subscale scores are transformed to a 0-100 scale</p>		<p>The QLQ-C30 is a copyrighted instrument. You are required to sign and return a User's Agreement form before using the QLQ-C30. Translated into 43 languages</p>
<p>Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1992)</p>	<p>Measures various mood states (e.g., tension, anger, depression, confusion). Dimensions of affect or mood and has proved to be useful for assessing psychiatric outpatients and their responses to various therapeutic approaches.</p>	<p>The POMS consists of sixty-five adjectives describing feeling and mood to which the client responds according to a five-point scale. Hand scored or optically scanned for computer processing</p>	<p>Ages 18 and older, 3 -5 minutes 8th grade reading level,</p>	<p>Can be purchased from http://www.edits.net/products.htm Source: Educational and Industrial Testing Service P.O. Box 7234 San Diego, CA 92167 Phone: 619-488-1666 E-Mail: edits@k-online.com</p>

C. INTERVENTION RESEARCH USING EXPERIMENTAL DESIGNS

Exploratory and survey research using both qualitative and quantitative methods can yield many insights and greater understanding of how cancer patients and their families are impacted by the cancer experience. Based on these findings and theory development, interventions can be developed. The next step is to test the efficacy of these interventions. Do our clients feel these interventions are helpful to them? Do the interventions lead to their intended results, such as less depression or anxiety, greater knowledge about their illness, improved family communication or improved coping strategies?

Intervention research designs tend to fall into one of the following categories:

Single Subject Designs

This design is used for individual clients in contrast to the more common designs using groups of clients. A quantitative measure of a target condition, usually a behavior or an emotion, may be selected then used repeatedly at different points in time. A baseline, or control phase, of three or more measures is recorded on a graph before the intervention is begun. The intervention is then introduced, and more measures are taken to determine if improvement has occurred. This is referred to as an AB design with A designating baseline phase and B designating intervention phase. More sophisticated designs are described in Rubin and Babbie (2001).

The logic of the single subject design is used in patient care in medical settings. For example, a patient with high blood pressure is placed on medication. A few weeks later the blood pressure is measured again and changes in medication are made if needed. An oncology social worker might use a single subject design in the following way. A patient with a needle phobia is referred to you for relaxation training and systematic desensitization. You might use a self-anchored rating scale similar to the pain scale with one being no anxiety and 10 being intolerable anxiety. Relaxation training is then started. The patient is then asked to visualize the

approach of a needle and the 1-to-10 scale is again recorded. This process is completed until the anxiety level becomes manageable.

Advantages and Disadvantages of Single Subject Designs:

A single subject design can be used to evaluate the efficacy of your own clinical practice and when done for this purpose, is not usually subject to IRB approval. However, if you intend to use an intervention on several clients, record your findings and later publish the results, then you will likely need IRB approval. Consult your IRB to learn their interpretation and policy. Another advantage of the single subject design is that you get immediate feedback about whether the intervention is working for your client without waiting for group design results that rely upon averaging client data across the group. In other words, an intervention may help 70 percent of patients, but your patient is not among those helped. The single subject approach may also be helpful in pilot testing an intervention with a small number of clients. You could then make changes as indicated before committing time and energy to enrolling larger numbers of patients in an experimental group design.

Quasi- Experimental Designs

The most familiar of these designs is the **one group pretest posttest**. A pretest using a standardized instrument such as the Brief Symptom Inventory, the Profile of Mood States, or other measure of your target condition is administered. Subjects are then provided the intervention such as a type of support group, a problem-solving intervention or an educational workshop. Upon completion of the intervention a posttest is administered, and sometimes the posttest is administered again one to three months later to determine if there were lasting effects of the intervention. Walsh-Burke (1992) used a one group pretest-posttest design to measure changes in family communication resulting from the We Can Weekend program. Similarly, Roberts, Piper, Denny, and Cuddeback (1997) used this design to learn if young adults with cancer showed improvement in their psychological well-being after attending a support group designed for them. Although analysis of results is done using groups of patients, it is important to remember that the design can be used when you are providing interventions individually as well as in groups.

Advantages and Disadvantages of Quasi-Experimental Designs: Since no control group is used, smaller numbers of patients are needed. Further, all subjects who wish to participate are provided the intervention. The pre-test, post-test design, however is weak in internal validity - the knowledge or assurance that change actually is attributable to the intervention. For example, an obstacle to concluding the subjects improved, as the result of the intervention is "maturation." This refers to the fact that many people who have undergone a trauma will get better with the passage of time, regardless of whether they were exposed to an intervention. In spite of the limitations, a one group pretest-posttest design is an excellent way to learn if an intervention has potential.

The Classic Experimental Design

This design is referred to in medical settings as a clinical trial. Consenting patients are enrolled in the study knowing that they will be randomly assigned to the experimental group, which receives the intervention (perhaps a drug), or to the control group, which does not receive the intervention. In medical trials, the patients do not know if they are receiving the treatment or not, and frequently their physician does not know either. This is described as a double-blind study.

Although the classic experimental design is considered the "gold standard" as it has good internal validity and generalizability, it is difficult to implement unless you have sizable resources and grant support. Blanchard, Toseland and McCallion (1996) were able to use an experimental design with a control group when they examined a problem-solving intervention with spouses of cancer patients.

A variation of this experimental design is the waiting list control group design. Consenting patients are randomly assigned to a treatment or control group, with the latter patients being placed on a waiting list. Both groups are administered a pre-test and upon completion of the intervention, a post-test. The waiting list group are then immediately given the intervention, and upon completion, another post-test. This design overcomes the ethical objections to withholding treatment from patients who could potentially benefit from it. Roberts et al (1997) had intended to use the waiting list control

group in their study of the support group for young adults with cancer. However, they were unable to enroll a sufficient number of subjects at one time to randomly assign half to the waiting list group.

Current Definitions of Interventions

Pioneering research on psychosocial interventions in oncology focused on interventions such as long term groups (Spiegel, Bloom & Yalom, 1981) structured, short-term groups (Fawzy et al., 1990) and individual therapy using at least six treatment sessions (Blanchard, Toseland, & McCallion, 1996). Some recent research, however, has focused on brief interventions such as watching a 20-minute videotape on one occasion. In conceptualizing intervention research studies, we should broaden our thinking about the interventions provided by oncology social workers.

D. A MINI-COURSE IN STATISTICS

Social work education is focused heavily on understanding human behavior and acquisition of practice skills. Hence, it is unlikely that you as an oncology social worker have had more than minimal training in statistical analysis or use of computer programs to analyze data. Consequently, our discussion of statistics will be divided into three sections. The first section will be a brief general overview of types of statistics. The second section will provide suggestions about where to find help with statistics. The third section provides more in-depth information on managing and analyzing data. Hint: If you read sections 1 and 2 diligently, you can skip section 3!

I. Overview of Statistics

There are two types of statistics. The first are **descriptive statistics** and include those we are all familiar with, namely, (1) total numbers (referred to as frequencies) of subjects, behaviors, counseling sessions, etc., (2) averages (which statisticians call "means"), and (3) ranges that are usually stated as lowest value to highest value (ex: the patients' ages ranged from 30 to 72.) Many informative research findings involve descriptive statistics. For example, the study completed by the Social Work Oncology Research Group (SWORG) made a valuable and often

cited contribution to the literature (Zabora, et al., 1997) when it found that 35% of cancer patients surveyed showed evidence of psychological distress. In another study using descriptive statistics, Johnson, Roberts, Cox, Reintgen, Parsons and Levine (1996) discovered that 74% of newly diagnosed breast cancer patients wanted their physicians to make recommendations for treatment and, when given, 94% followed the recommended treatment plan.

Second are **inferential statistics**. Although there are many inferential statistics, some of those commonly used in social work are the Chi square, Student's t-test and Pearson correlation coefficient. Inferential statistics help us determine whether apparent differences in our data occurred by chance alone. If the probability of the finding occurring by chance is less than five times in 100 ($p < .05$), we say the apparent difference is statistically significant. For example, let us say that you are evaluating a support group intervention by doing a pre-test and post-test of depression scores. If you had ten subjects in your group and their depression scores improved by dropping an average of two points, could you conclude that your support group was effective or did the two-point drop occur by chance alone? A paired t-test would tell you if the two point drop was statistically significant and not simply due to chance. It is important to know which inferential statistic is appropriate in your data analysis. This will be covered in greater detail below.

2. Where to Find Help with Your Statistical Analysis

A good resource for help is the Chair of SWORG, who is identified on the AOSW Website at www.aosw.org. After designing your study and selecting or developing an instrument, contact the SWORG Chair, who will attempt to provide advice or put you in contact with research-trained SWORG members who may be interested in collaborating with you. Many of these persons are in academic settings where they are encouraged to conduct and publish research and are generally eager to pair up with clinicians who have access to patients and are doing interventions.

If you work in a major cancer center, there is a good chance that they have at least one full-time statistician working in a research or statistics department with whom you could consult. This person is generally involved in medical studies and may or may not be familiar with statistical techniques commonly used in the social sciences. However, it's worth a try.

A school of social work in your area may have a faculty member who would be willing to assist you with your statistics. Your first choice should be someone who has done clinical research (that involving data collection with patients or clients). Such a person can suggest methods and techniques that are feasible. This is an indirect way of saying you should avoid collaborating with "armchair researchers" or those who may teach statistics but are unfamiliar with the realities of doing research in clinical settings.

An additional resource is a person with a doctorate in a related professional field (medicine, nursing, public health) or social science (psychology, sociology, anthropology, economics), assuming she or he has done clinical research in health care settings.

3. Statistics in Depth: Managing and Analyzing Data

If you decide to handle your own statistical analyses, you will need a way to manage the data. Further, you will need to select and use the proper statistics.

Managing data

As you collect respondents' completed instruments, you will need an organized procedure for recording these data. As numbers are assigned to every response on a questionnaire, these numbers must be entered into a computer database, such as Microsoft Excel or Statistical Package for the Social Sciences (SPSS), in order to manipulate and analyze them.

All data from instruments are coded into discrete (also called categorical) variables or **continuous** variables. Types and examples of these variables are listed in Table 3.

Table 3: Discrete (categorical) and continuous variables

Variables	Examples
Discrete (or categorical) Nominal – Responses represent different categories, with the value of any one category being no different than the value of any other	Religion, Gender Race/ethnicity
Ordinal – Variables in which response categories represent a gradient or order	Social class (low, middle, upper) Likert scales (responses range from 1 = not at all to 4 = a lot Rankings, Preferences or Choices (First, second, third)
Continuous Ratio or Interval – Variables that increase steadily at a constant rate	Age Number of hospital admissions or days in hospital Summary score from the Brief Symptom Inventory (BSI) or most standardized instruments

Analyzing data

Statistical analyses of survey data allow you to characterize your sample and draw conclusions about subjects' responses to the questions you have asked them. **Descriptive statistics**, as mentioned above, are used to examine the characteristics of your sample or results on questions you have asked.

Measures of association allow you to compare how

different groups respond to questions. Finally, **tests of statistical significance, also known as inferential statistics**, will help you determine whether differences you observe are "real" and not simply due to chance. Table 4 provides examples of common statistical procedures.

Table 4: Common statistical procedures

	Examples	Common Statistical Procedures
Descriptive statistics	<ul style="list-style-type: none"> • 35 males, 46 females • Average test score • Proportions of attendees who found a program excellent, very good, fair, and poor 	Frequencies, percentages, mean, median, mode, range, minimum, maximum, standard deviation
Measures of association	<ul style="list-style-type: none"> • Scores differ across two or more groups (males/females; breast, prostate and lung cancer patients) • Quality of life scores increase as age of respondents decrease 	2x2 tables (Crosstabs), comparison of means, Correlation coefficients
Tests of Statistical Significance	<ul style="list-style-type: none"> • Symptom distress scores are statistically significantly greater for females than for males 	Student's t-test, Chi-square, Analysis of Variance (ANOVA), Pearsons correlation coefficients

Prior to examining your data, it is helpful and important to distinguish **dependent** variables (also called outcome variables) from **independent** variables (sometimes referred to as predictor variables). **Dependent** variables are those that represent the outcome in which you are interested. For example, your research question may be an examination of distress levels at time of diagnosis, and your hypothesis is that distress levels are higher for patients who are alone at this time as compared to those who have family members present. Your

selected measures or questions that assess distress are your outcome, or dependent variables. According to your hypothesis, these scores will *depend on* (thus their name - dependent variable) whether or not a person is alone when told of their diagnosis. The patient's status at the time they are told of their diagnosis (alone or family members present) is the **independent**, or predictor, variable since you are suggesting that their status will predict, or be associated with, a higher or lower distress score.

Table 5 will guide you in selecting appropriate tests of statistical significance, depending upon the types of dependent and independent variables you have measured.

Table 5: Guide for using common and appropriate statistical tests to determine statistically significant differences

<i>and the dependent (outcome) variable is...</i>			
		Discrete (or categorical)	Continuous
When the independent variable is...	Discrete (or Categorical)	Chi-square	Student's t-test; General Linear Models (i.e., Analysis of Variance, or ANOVA)
	Continuous	Logistic regression	Pearson correlation coefficient; General Linear Models (i.e. Linear Regression)

VI: QUALITATIVE RESEARCH METHODS IN ONCOLOGY SOCIAL WORK

Qualitative research is the study of people in their natural environment as they go about their daily lives. It tries to understand how people live, how they talk and behave, and what captivates and distresses them. More importantly, it strives to understand the meaning people's words and behaviors have for them (Tutty, Rothery, & Grinnel (1996), p. 4).

Qualitative research, then, provides an intentional way of learning about people's complex and poorly understood thoughts, feelings and experiences (Rubin & Rubin, 1995). Qualitative researchers look at small samples of people, nested in their context, and studied in depth (Miles & Huberman, 1994). One tries to make sense of everyday life as it unfolds, without interrupting it. An inductive method of analysis is used to allow important dimensions to emerge from the data, without presupposing in advance what those important dimensions will be (Patton, 1980).

The result is a rich, "thick", well-grounded description of a phenomenon. Qualitative methods can also be used to explore a new area or develop hypotheses. When little is known, a rich understanding based on a few persons' experiences may provide a hypothesis from which to develop further research. It can also be used for testing hypotheses by examining whether specific predictions hold up under questioning members of a particular group or population. Finally, "qualitative data are useful when one needs to supplement, validate, explain, illuminate, or reinterpret quantitative data gathered from the same setting" (Miles & Huberman, 1994, p. 10).

Qualitative research methods are user-friendly for individuals in psychosocial clinical oncology practice. The clinical psychosocial assessment and charting are examples of collecting and creating informative data to be analyzed at a later time. Because qualitative inquiry is used for (1) describing a phenomenon about which little is known, (2) capturing meaning, and (3) describing a process rather than an outcome (Mayan, 2001), there are many questions in psychosocial oncology that apply.

Qualitative methods are a way to capture the experiences of patients and their families, to analyze what's happening in groups, to study a case or cases in a specific way, or to better understand any poorly understood phenomenon in oncology. Any of these may result in a new theory or suggest new or improved treatment approaches.

Sources of qualitative data

Qualitative researchers use multiple means to gather data. Sources of data may include one or several of the following:

Primary Data (Glesne & Peshkin, 1992):

- Individual interviews captured on audio or video tape with observation field notes
- Groups such as cancer support groups or focus groups with field notes, diagrams of speaking patterns, audio or video recordings
- Case studies might include transcribed audio taped sessions, assessment notes, chart review, and field notes of observations of verbal and non-verbal communication. Sometimes the subject's personal journals, poetry, or other writing is included as data. Notes of ethics committees might be relevant to any study.

Secondary data (Stewart & Kamins, 1993):

- Government documents such as census data
- Agency reports, such as the annual ACS Cancer Facts and Figures

Using multiple sources of data, or triangulating data, strengthens the findings of the study. This means collecting data about the same issue or topic from different perspectives. An example might be investigating the role of spirituality on patient well-being, wherein you might interview patients, family members and health care providers. Findings will be richer and stronger if you carefully set out to collect and double-check findings, using multiple sources and modes of data.

Selecting a research technique for a qualitative study

There are many branches of qualitative methods and analyses. Choosing the one right for a study requires careful consideration of the question to be researched, the appropriate sources of available data to answer that question, and type of analysis that best fits the question.

A few qualitative research techniques are described in Table 6 below. We suggest taking a look at the examples as models for the technique.

Technique	Examples
<p>Ethnography involves “prolonged observation of a group through participant observation (or fieldwork) so that researchers can immerse themselves in peoples’ day to day lives” (Devers, 1999).</p>	<p><i>Healing Children’s Grief</i> (Christ, 2000). A study of children, whose parents were dying, involved interventions spanning about 14 months and included six or more 60-90 minute interviews during the terminal stage of the illness, and six or more after the death.</p>
<p>Phenomenology focuses on the lived experiences of individuals and of their experience of the world around them (Barnard, McCosker, & Gerber, 1999; Morse & Field, 1995).</p>	<p>A study of the meaning of having ovarian cancer for women during childbearing years (Schaefer, Ladd, Lammers, & Echenberg, 1999). This study offers an in-depth understanding of the meaning of the experience of living with ovarian cancer in the participant’s own words.</p>
<p>Grounded theory is basically developing theory inductively from the intense study of the words and observed behaviors of the participants. It is used to answer questions concerning the process of an experience (Morse, 1994, Strauss & Corbin, 1990).</p>	<p>Sanden and Hyden’s (2002) report on a study of relatives of men suffering from testicular cancer. The central question was how the disease and its treatment affected the life of the family. Another example is Jones’ (1999) report on women’s decision making process around hormone replacement therapy.</p>
<p>Narrative research is the study of a person’s story. The purpose is to see how the person imposes order on the flow of experience to make sense of events and actions in his or her life (Riessman, 1993). It “examines the person’s story and analyzes how it is put together, the linguistic and cultural resources it draws on, and how it persuades a listener of authenticity” (Riessman, 1993. P. 4).</p>	<p>“Making Sense of Marital Violence: One Woman’s Narrative” (Riessman, 1994) examines how one woman reconstructs and reinterprets her experience of being sexually abused by her husband.</p> <p>In a recent publication by Kacen (2002), abused women were asked to define the “story line” of their lives. Analysis of the titles that interviewees gave their life stories embodied several themes.</p>
<p>Case Study Research is often used to answer “how” and “why” questions and provides rich descriptions of individuals’ lives in context (Gilgun, 1994). This approach may involve data collected from single or multiple cases.</p>	<p>Case Study Research is used to illustrate family dysfunction that can occur when a woman who has assumed the role of primary care giver is diagnosed and treated for cancer (Roberts, Baile, & Bassett, 1999).</p> <p>Hill (1986) demonstrates the importance of exploring one’s feeling during the time a woman with breast cancer must decide between mastectomy or lumpectomy.</p> <p>In a study of the effect of contemplated physician-assisted suicide on hospice social workers, eight social workers shared their personal and professional voices about a very controversial and difficult issue (Miller, Mesler, & Eggman, 2002).</p>
<p>Focus Group Research relies on interaction within a group, based on topics that are supplied by the researcher who typically takes the role of a moderator” (Morgan, 1997, p. 2). The key to focus groups is that attitudes and perceptions are not developed in isolation, but through interaction with other people (Morse & Field, 1995). Typically, a focus group consists of six to ten participants, and consists of three to five groups of participants (Mayan, 2001; Morgan, 1997).</p>	<p>Wright, Kiely, Lynch, Cull, and Selby (2002), describe, evaluate, and categorize social problems experienced by 96 cancer patients. The social problems identified in these focus groups contributed to an item pool generated for developing a Social Problems Inventory that may be included in a patient-centered assessment of routine oncology practice (Personal communication, Penny Wright, 11-19-02).</p> <p>Another focus group report is “Women Like Me: Reflections on Health and Hormones from Women Treated for Breast Cancer” (Bond, Hirota, Fortin, & Col, 2002). In this study, the focus group participants were women who were living with breast cancer and could not take hormone replacement.</p>

Technique	Examples
<p>Mixed methods: Using both qualitative and quantitative methods in the same study is called methodological triangulation. The mix can occur either sequentially or simultaneously. Integrating qualitative and quantitative data collection techniques provides a more comprehensive approach to research and takes into account more fully the complexity that is at the heart of social work practice (Allen-Mearns & Lane, 1990).</p>	<p>Mixed methods are used in a study to answer the question "To what extent is the quality of life for cancer survivors associated with current age or life stage, age at diagnosis, existence of delayed or long-lasting physical effects, and socio-demographic status?" (Zebrack, 2000). Grounded theory produced inductive findings on the qualitative aspect of the study while use of a standardized instrument to measure quality of life produced results across several dimensions.</p> <p>Mixed methods are often used to evaluate programs. One study evaluated the impact of the "We Can Weekend" on family communication and coping with cancer (Walsh-Burke, 1992).</p> <p>(Damore-Petingola, Lightfoot, Vaillancourt, Mayer, Steggles, & Gauthier-Frohlick, 2002) evaluated a video program depicting the experiences of young adults whose parents were diagnosed with cancer.</p>

Steps of analysis using content analysis

Content analysis is one method of analyzing qualitative data, and is presented here to demonstrate the rigor of qualitative analysis. These steps are not meant to discourage you, but are included for those of you who find these methods attractive. The first time you conduct qualitative research, it might be helpful to have an experienced colleague as a mentor. If you do not have someone available to you, an attempt will be made to find this assistance through AOSW by contacting the current SWORG chair.

Content analysis involves an inferential process of coding text into content categories. Words, phrases, or other units of text are classified into categories, which are inductively derived (Krippendorff, 1980; Weber, 1990). An inductive strategy means dimensions emerge from the analysis itself. Inductive coding forces the researcher to treat each datum as new discovery and explicitly works against coding to an existing paradigm (preconceived notions of how one might think the data would be organized).

Since content analysis is the study of text, sources of data may be any written communication. In this example, we will assume the data are from taped interviews of people representing the phenomenon we wish to better understand. We will also assume that the researcher has purposely chosen qualitative research based on a research question, which is best answered with an inductive analysis of content.

Preparing and managing data are complicated tasks in qualitative research. Ensuring that the data are accurate is essential. The first steps of the process, then, have to do with developing the data. (The following steps are further described in Lewis & Deals, 1995, Behar, 1999, and Mayan, 2001).

Step 1: Interviews are transcribed verbatim (with every um and aw), revealing no identifying information of the subject. Notes may be interjected into the transcription, such as [crying], [child interrupts interview], etc. Bracketing delineates the words of the researcher as opposed to the exact words of the subject.

Step 2: Transcription is then verified by re-listening, word for word, to the tape recorded data and editing the transcriptions. This is an important step as the research results are only accurate if the data are exact.

Step 3: Data are read in full, three times, before units of analysis are considered. The purpose of this is to focus on messages in the data as a whole, before breaking data into units.

Step 4: Initial Coding: Units of analysis are then identified in the data. These may be established as persistent words, complete ideas, phrases, themes or concepts. All units of analysis are coded - none are discarded. The purpose of initial coding is simply to start to organize the information. At this point, management of data becomes difficult and extremely

important. There are computer programs to help organize analysis, but careful coding into files can be done by hand, as well. The important thing is to be diligent in organizing data. One way to do this is to highlight sections of text, making comments in the margins regarding anything that is striking.

Step 5: Categorizing: Data are then cut and pasted (literally or in a computer program) and grouped into categories and subcategories in separate files or folders. The categories are labeled with emic labels (categories identified by the words of the participants) as much as possible. This process involves constant comparative analysis, occurring throughout the research process from initial data collection through coding to final analysis and writing. It involves the process of inspecting each piece of data, categorizing it with other like data or establishing it as part of a new aspect of a phenomenon under study.

Step 6: Refinement of open coding and initial categories: This is to re-emphasize that this is a circular process which requires much comparing and rethinking, coding and re-coding, until refinement and definition of categories is inclusive and compatible with all data. The data are put together in ways that make connections between categories, by discovering the relationships among the categories and finding common threads or themes that run through the data (Mayan, 2001).

Step 7: Core construct identified: The core category is "the central phenomenon around which all other categories are integrated" (Strauss & Corbin, 1990, p. 116). At this time, the initially identified categories are reorganized into higher order domains around the core category (Lewis & Deal, 1995).

Step 8: The result of the constant comparative analysis and organization of categories and domains is the development of an explanatory theory. This theory is then reviewed and critiqued, with further refinement, leading to the development of a final version of explanatory theory.

With the completion of a qualitative study, one reviews the literature to see if other studies have illuminated similar theory. (Whether to do the literature review before or after a study is debated and must be determined by the researcher.)

Sometimes it is possible to link a developing theory into other studies. Sometimes developing theory points to further studies to expand knowledge gained in another qualitative study, or suggests testing the theory across large numbers of people in a quantitative study.

An example of content analysis is Arnold (1999), *The Cessation of Cancer Treatment as a Crisis*. In this article, she analyzes the narrative responses of seven cancer patients asking them to describe their experiences since their treatment ended. After the data were examined for emerging themes and categories, the author returned to the literature and integrated the findings with a review from the existing literature. This process provides the reader with a clear picture of women's experiences in the context of previous research (Arnold, 1999).

Ensuring good qualitative research

Establishing credibility and utility (usefulness) is as important to qualitative research as are validity and reliability to quantitative research. The concepts differ because validity and reliability generally refer to measurements used to measure associations among variables. Credibility refers to the ability of the researcher to present and interpret findings that are worthy of attention. Mayan (2001) suggests four areas for establishing trustworthiness, drawn from the work of Lincoln & Guba (1985).

- Credibility refers to the "truth" of the findings, as viewed through the eyes of those being observed or interviewed. The question is, "did we get the story right?"
- Transferability is the extent to which findings can be transferred to other settings. This is the degree to which the readers of research are able to transfer the research findings to contexts outside of the study situation to other settings (Mayan, 2001), making the findings applicable and useful to their area of interest.
- Dependability has to do with the extent to which the research would produce similar or consistent findings, if carried out as described by someone else.
- Confirmability requires researchers to provide evidence that corroborates the findings. This evidence should come directly from subjects and research context.

There are several strategies that can be used to ensure rigor in qualitative research.

- Using multiple sources of data, investigators, methods, or theories (triangulating) to the extent possible, provides corroborating evidence and helps ensure credibility and confirmability (Devers, 1999).
- Searching for disconfirming evidence, and refining theory and working hypotheses in light of this evidence, helps ensure credibility and confirmability (Devers, 1999).
- Participant checks involve the researcher(s) checking or verifying developing hypotheses, preliminary categories, and interpretations with members of the target populations, or populations of interest, to ensure that the researcher has interpreted or is interpreting findings as the subjects meant them to be. This strategy is used to ensure credibility (Devers, 1999; Mayan, 1999).
- Critical Peer Reviews require engaging another researcher in an extended and extensive discussion of findings, conclusions, and tentative analyses, to help the researcher critically question the process and emerging hypotheses (Morse & Field, 1995). This person plays the role of devil's advocate, asking difficult questions about methods, meanings, and interpretation of the data. This helps ensure confirmability, dependability and provides an external check on the research (Devers, 1999).
- Reflective journal writing by the researcher helps keep the researcher honest. The researcher, as the research instrument in qualitative research, keeps journal notes on how his or her personal characteristics, feelings, biases, and assumptions about the research may influence the work. S/he also keeps notes on how these possible biases are managed. This helps ensure confirmability (Devers, 1999; Mayan, 2001).
- An audit trail is a map for any researcher or auditor to clearly follow the decision trail used by the researcher in the study (Mayan, 2001). This requires a carefully identified trail of raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, and materials relating to intentions and dispositions (Lincoln & Guba, 1985). The audit would examine the process, attesting to the dependability and confirmability of the inquiry (Devers, 1999).

After analyzing your data, the next phase is to present your material to colleagues, obtaining feedback which will propel you into publishing your

material (See Section IX). We hope you will enjoy qualitative research and that it will "fill your soul" with its richness.

VII: PROTECTION OF HUMAN SUBJECTS IN RESEARCH

Research involving human subjects must be approved by the Institutional Review Board (IRB) to ensure that the research plan has both scientific merit and safeguards to ensure the protection of human subjects. To learn about the history, ethical principles and guidelines for protection of research subjects, we recommend you take the web-based course at <http://cme.nci.nih.gov/>. It takes about 20 minutes and results in printing out a completion certificate in your name. Most institutions require that all researchers complete this course or an equivalent.

Once you have been introduced to the vocabulary used by all IRB's, you are encouraged to make an appointment to talk with the IRB administrative personnel in your setting. These behind-the-scenes people can give you an IRB application (or direct you to an electronic version on a web site), inform you of submission deadlines, show you examples of Informed Consent Forms, and ultimately be very helpful in securing approval.

Getting IRB approval can be a challenge, as Board members may be critical of your study and usually take their task of protecting human subjects, i.e. the patients in your institution, very seriously. We offer the following tips: (1) Talk to someone who has recently gone through the process and ask to review their application. It will help you learn terminology used to answer the questions. (2) Ask if you can attend an IRB meeting before you are ready to submit your application. Much of the meeting should be open to the public. (3) Understand that most IRB's are accustomed to reviewing clinical trials, which use sophisticated experimental designs. Reviewers may need to be educated about the state of the art of social or behavioral research. In larger institutions a separate Board may review behavioral studies. (4) If you are a member of AOSW, contact the SWORG chair for assistance in preparing your application. (5) Be philosophical. If your study is not approved the first time, make the requested revisions and resubmit it.

VIII: THE CASE FOR COLLABORATIVE RESEARCH

It is rare to find research in oncology settings, or indeed in any health care setting, that is done by a single individual. Researchers who are making their first efforts are encouraged to seek out opportunities for collaboration in order to “learn the ropes.” Here are some suggestions for collaboration:

1. Talk with social work colleagues at your institution about your interests.
2. After you have formulated a research plan, discuss it with the physicians on your team to determine their interest in it. Many physicians are eager to be co-investigators and will facilitate your access to their patients as research subjects.
3. Seek out experienced psycho-oncology researchers to learn if they are interested in having you aboard. Their projects and interests may not be the same as yours, but you will learn a lot from being part of their team. Just ask them what you might be able to contribute to their work.
4. Ask about pharmaceutical or medical studies being done by members of your interdisciplinary team to determine their interest in adding a quality of life arm. You may suggest a Quality of Life measure that can be added to the study with you taking responsibility for analyzing and reporting the results.
5. Determine if there are social work faculty members in your area who have a background or interest in oncology and/or health care social work. Remember their assignments include research activities, and they may be delighted to collaborate with you as you have access to patients and they may not.
6. Join the Social Work Oncology Research Group of AOSW (SWORG) to learn about collaborative projects which are planned or underway.
7. Look for statisticians in your facility to help with research design and statistical analysis. Social work faculty or other doctorally trained persons can assist with this as well.

IX: DISSEMINATING RESEARCH FINDINGS

Disseminating research findings may be accomplished via: (1) professional presentations and (2) submission of a manuscript for publication. Experienced researchers frequently present their findings first, then incorporate feedback from the audience in their manuscripts. In this section, we will provide suggestions for both successful presentation and publication of your research results.

A: Presenting

There are likely opportunities for presenting your research all around you. Hospital rounds or interdisciplinary team meetings provide excellent settings for social workers to talk about their research. Your colleagues will benefit from learning about your findings, and your professional status as a social work researcher will be established. Other examples of presentation opportunities are local Social Work in Oncology Groups (SWOG's), and local, national, and international conferences – especially AOSW! Sometimes research is appropriate to share with patient and family groups. Don't hesitate to offer to present in multiple venues. It is the best way to begin to share information and to learn what aspects of your research are valuable to different groups in their work.

Planning your Presentation

Who is your audience? What would they particularly like to hear about your research? For instance, if your audience is mainly made up of researchers, they will want to know more about your research methods than an audience of mainly clinicians. Ask yourself how your research can help them in their work? What might they like and not like about what you have to say? Also think about how big your audience might be and develop a format that will work for the size of group.

How much time do you have to present?

Remember to leave ten to twenty minutes for questions, either throughout your talk or at the end. This varies with the size of the group and the format of the presentation (conversational vs. lecture). A

common mistake for an inexperienced speaker is to come in with enough material to fill the entire time period **IF** one talks fast enough and doesn't breathe too often. This is not a good plan! Time goes FAST!

What is your message? What are the most important aspects of your research to present during the time given? The most common pitfall of research presentations is not leaving time to thoroughly discuss the findings. It is important to state the purpose of your study and why/how it is important, as well as explaining your research methods, but keep these sections short so you can focus most of your time on the findings and ensuing discussion. Be a storyteller. Focus on main points and avoid too many details. Encourage audience participation in the discussion of findings and implications for clinical practice and/or further research.

What kind of audiovisuals will you use? Know what equipment is available. Power Point slides have become popular, but renting the equipment is expensive. Slide projector slides work nicely, as do overheads. Flip charts can be used to increase audience participation. Plan to use slides for key words, phrases, statistics, and tables to support and reinforce the presentation. Interspersing jokes can add impact and build audience rapport. Be sure everyone in the audience can see and read the slide. Show the slide only while you are talking about that slide. Limit writing on slides to a few lines. Don't overdo the use of slides - there is a point of diminishing returns. Slides should be used as a form of emphasis, but when everything is emphasized, the major points are lost. It is often helpful to have copies of your slides as a handout. One format allows for notes beside the slides (3-5 slides on the left side of the page with lines on the right) so attendees can keep note taking to a minimum. This has the added benefit of a back up if your equipment fails, and as an outline so your audience can look back at a slide, or look forward to be sure their question will be answered.

Practicing: A big part of planning a presentation is practicing what you want to say. Practice out loud in front of a mirror. Practice with notes and learn to "talk" without reading. Utilize shorter sentence structure than you would for writing. Use clear language. Utilize pauses. Practice, practice, practice! Ask a peer to listen to your presentation and provide feedback. Check your timing and be sure you have

plenty of time for discussion. Be certain to stay within your time limits to convey respect to your audience.

Organizing your Presentation

Research presentations generally follow a standard format and include the following:

- Title and Presenter: Be sure to acknowledge collaborators.
- Background Information: Briefly summarize previous research.
- Purpose of the Study: State this succinctly
- Methods: In this section describe each of the following:
 - Research Design
 - Subjects: Provide demographic and clinical characteristics. Mention informed consent procedures and IRB approval of your study.
 - Instruments: Describe the standardized instruments used as well as researcher designed instruments such as interview guide.
 - Procedures: How, when and where were data collected?
- Results: Provide an analysis of your data
- Discussion of Results/Findings
- Implications for Practice and/or Future Research
- Summary: Recap the major conclusions of your study

Although we know of no perfect formula, we believe that about one third of your presentation should be spent on background, purpose and methodology with the remaining two thirds devoted to your findings and the practice implications.

Delivering the Presentation

The day has finally arrived. You are confident, excited, ready! OR scared to death. OR both. Here are some tips that might help.

- Go to the room ahead of time to see it and to check out equipment. Set up your materials.
- Be audience centered. As the audience enters the room, introduce yourself to people and ask them questions about themselves, their work, and their interests. This will help you see your audience as "real people".

- Before you speak, push out the butterflies with a deep breath.
- Start with high energy. Develop rapport with the audience. Establish credibility as a speaker. Make your first sentence memorable. Tell a short story as a lead-in to what you are going to talk about.
- Stand firmly and gesture expressively. Move your body. Be yourself. Use facial expressions that are natural to you. Be passionate!
- Talk to their eyes. Face the audience - don't talk to your slides.
- Pitch your voice to the rear of the room. Vary tone for emphasis. Use your voice and emphasize key ideas. Four vocal techniques develop contrast: Volume, pitch, rate, and pausing.
- Deal with questions effectively. Anticipate, listen to and repeat questions. Analyze the question, and if you don't know the answer, say so. Recognize the value of the question and link it to a broader issue when appropriate. When possible, identify sources of additional information.

(Much of this material was developed by Susan Hedlund for presentations at AOSW Conferences, 2001 and 2002.)

A Word about Poster Presentations

Poster presentations differ from group presentations in that you actually tack your work up to a poster or bulletin board, often 4 feet by 8 feet in size. A major advantage of a poster presentation is the opportunity for one to one interaction with colleagues who are interested in your research topic. The poster itself should contain the same basic information outlined above. An attractive poster, which contains this material, is a good way to highlight your research and initiate discussion.

B: Publishing

Publishing sounds like such a scary proposition when you are a new author. On the other hand, thousands of people publish every day, so, why not you? Right? Writing up and reaching practitioners with your findings is the final and most critical phase of the research process.

You may have an article that you have considered publishing, or an idea that you think is worth

writing for publication. You may have research findings, either positive or negative, that need to be disseminated to others in the field. The big question is where to start. This chapter is to help you find success in publishing.

The first step is **choosing a journal**. "But just a minute", you say. "I haven't even written this article yet!"

All the better!

Choosing a journal allows you to write to the readers of that journal, and to structure your writing to the journal's specifications and guidelines, saving yourself some valuable time in the process. In asking yourself where to publish, the first question is, "Who is my intended audience?" Do you most want this information to reach physicians, nurses, other health care professionals, oncology social workers, social workers in training, patients or family members? Is this article intended for a research/academic audience, or for a practice-oriented audience? Answering these questions allows you to narrow your focus to the journals you wish to review. One way to start to **locate a journal or publisher** is to ask active and published researchers or colleagues where they published, and why. Then, or alternatively, it's important to **review journals** that might be possible choices for your particular work.

In reviewing journals, find out if the journal publishes the type of work you want to submit. For instance, *Research on Social Work Practice* accepts only "original reports of empirically based evaluation studies on the outcome of social work practice; reports on the development and validation of new methods of assessment for use in social work practice; and empirically based reviews of the practice literature that provide direct applications to social work practice" (taken from the cover of *Research on Social Work Practice*, 12:6, November 2002). If your work doesn't fit into that description, you will want to look further.

Another observation, in reviewing journals is whether the journal prints articles that are similar to yours. Journals tend to carve out their own special niche, preferring depth to breadth. The publisher most likely to publish your work publishes similar work. When submitting, you may include a cover letter that describes how your work will complement their published articles (Wolcott, 1990).

Don't be afraid to contact journal editors if you are unsure whether the content of your work fits within the journal's scope. It might also be prudent to ask about the average length of time from submission to publication, how quickly an article is reviewed, and when you can expect to hear from them. One journal editor once admitted that she was backed up for two years. That was important information to know!

Some journals to consider for psychosocial research in oncology follow:

- Journal of Psychosocial Oncology, the official journal of AOSW
- Psycho-Oncology
- Social Work in Health Care
- Health and Social Work
- Qualitative Health Research
- Research on Social Work Practice (not usually recommended for beginners)
- Social Work, the official journal of NASW (not usually recommended for beginners)

Do not forget to consider nursing and medical journals. Some examples are:

- The Breast
- Breast Cancer Research and Treatment
- Cancer
- Cancer Nursing
- Family Relations
- Health Care for Women International
- Health Psychology
- Journal of the American Medical Women's Association
- Journal of Behavioral Medicine
- The Journal of Family Nursing
- The Journal of Surgical Oncology
- Nursing Research
- Oncology Nursing Forum
- Preventive Medicine
- Psychosomatics
- Social Science and Medicine

If you want to publish a clinical article for patients and families, you might want to consider:

- Coping Magazine
- CURE

Choosing a journal is a big step. An article may only be submitted to one journal at a time, so you want to choose a journal where you have a good chance of getting your work published.

Once you have chosen a journal, get a copy and read carefully the Instructions for Authors. It is important to submit exactly as they request. Generally, a "complete instructions for authors" is available from the editor. For most journals, you will submit a manuscript with up to 20 or 25 double-spaced pages including references and abstract (each journal is different). Your abstract will be limited to approximately 100 words, depending on the journal. Each journal asks for a specific number of copies, sometimes a diskette, return envelopes, etc. It is important to check, and double check, these requirements.

Because this is a research manual, we are writing from the perspective of reporting on research. You may, on the other hand, be writing a review of pertinent literature (See Cwikel, Behar, Zabora, 1997), or a paper on clinical practice (See Roberts, Baile, Bassett, 1999). In a survey of practitioners who have published (Staudt, Dulmus, & Bennett, 2003), the authors said they were motivated to write because they had a desire to contribute to practice, and they added that they found academic contributions to the field not helpful to them. Oncology social work practitioners have much to contribute to the building of the profession's knowledge base.

When writing an article to report research findings, the following components should be included (Grinnell, 1993; Huff, 1999; Mayan, 2001; Tutty, Rothery, Grinnell, 1996):

Abstract: An abstract is a short statement that indicates the purpose of your study and its conclusions.

Introduction: The article should introduce the topic area and state the research problem, objectives and/or purpose of the research.

Review of the literature: Some journals want an extensive review, while others want a paragraph or two to show the reader why the study was necessary.

Research design: This section should include the specific research method, sampling strategy including demographic information and consent, the context including site and participants, data collection procedures, and steps of data analysis.

The researcher should describe the ways that reliability and validity were insured.

Findings: Findings are reported as a direct result of analysis, including the words of the participants to provide illustrations.

Conclusion/discussion: The conclusion is a discussion of the significance of your findings for your readers. The researcher summarizes the findings, discusses what they add up to, and where they may lead. (Hint: If the implications result in further research, the researcher should publish in a research journal, whereas if the implications suggest practice specifications, the researcher should focus on a practice journal.)

Limitations and recommendations: Limitations of a research study, particularly shortcomings that may affect how the findings are interpreted or applied, must be acknowledged. Recommendations might include specific further studies, practice suggestions, or changes in policies and programs.

Reference lists: The reference list includes all the articles, books, and monographs that you cite in your paper. References give credit to those that went before you and helped you learn more about what you are writing. They should provide the reader with further readings of interest. The reference style required by the journal is included in the Instructions to Authors. One of the common styles is APA Style. You can get all the guidelines from the APA Publication Manual (American Psychological Association, 2001).

Before submitting your manuscript, all spelling and grammar should be perfect. This may well require someone exacting to edit your work. No matter how careful you are, you will make mistakes. Tables will be printed as they are submitted, so check your math and edit the tables carefully. Reference formats are determined by the journal, but generally you will be asked to use the latest APA guidelines per above.

The **review process** can take weeks to months. Research on Social Work Practice states in their notes to authors that authors can expect an editorial decision within three months. However, many journals are not this prompt with their reviews.

Once you submit a manuscript, you should get confirmation that it has been received. The publisher then submits your manuscript to a blind peer review by two or three members of the editorial board. The editorial board of a journal consists of individuals who are chosen because of expertise in the subjects under review. These editors will provide you with a constructive review of your manuscript.

When you receive a determination from a journal, you will be told that the editors suggest the paper be (1) Accepted for publication, (2) Accepted for publication with revisions suggested, (3) Modified and resubmitted, or (4) Rejected. These should be accompanied by the reviewers' comments.

Expect revisions, at best! Very few articles are accepted for publication without revision. At first, getting several pages of revisions is daunting and feels insulting. Consider these a learning experience. If you have gotten to the point of revisions, you've made it! Make the revisions and resubmit. If you totally disagree with a suggested revision, prepare the manuscript for resubmission and send a letter explaining why you did not make the revision in question.

If you get a letter stating you should modify and resubmit, read the suggestions carefully. Usually it is prudent to modify and resubmit. It may be, however, that you chose the wrong journal, and the best thing is to incorporate their suggestions but submit to another journal.

If your article is rejected, learn from the comments, rewrite, and submit to another journal. You may find that there is a journal that would be much more appropriate for the work you are submitting.

Getting your work published involves thinking strategically, identifying the correct journal and preparing a report that will be acceptable to the reviewers of that journal. This takes perseverance and fortitude.

Publishing gets easier as you go. As with anything else, you will learn and grow from your challenges and successes. Happy publishing!

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APA web site for general information on how to purchase books and software:

<http://www.apastyle.org>

APA web site for information obtained from the Internet

<http://www.apastyle.org/electmedia.html>

APA style resources on the web.

<http://www.emunix.emich.edu/~ehoffman/apahelp.html>

Guidelines for Writing in APA Style written by William U. Borst, a graduate of Troy State University.

<http://www2.canisius.edu/canhp/departments/canpsych/borst.htm>

University of Wisconsin – Madison Writing Center

<http://www.wisc.edu/writing/Handbook/DocAPACitations.html>

University of Southern Mississippi

<http://www.lib.usm.edu/~instruct/guides/apa.html>

Capital Community College, Hartford, CN

http://webster.commnet.edu/apa/apa_index.htm



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