

STUDY OF OSTEOPOROTIC FRACTURES

Questionnaire Manual

This manual provides guidelines for the administration and interpretation of questionnaire items for the Study of Osteoporotic Fractures. It covers both the take home, or self administered questionnaire and the clinic interview questions. Pre-questions are designed primarily to assess known or suspected risk factors for osteoporotic fractures in older women, secondarily to assess behavioral and health history variables which may be related to bone mass and loss of bone mass. An overview of the scientific objectives and rationale underlying the choice of items can be obtained by reading the grant proposal.

The manual contains general guidelines for review and administration of questionnaire forms used in the study and detailed instructions for administering and interpreting specific items. This includes procedures for systematic review of take-home self administered questionnaires (SAQ). Instructions for coding are limited for those items which are to be coded during or soon after the interview. Coding for data entry is covered in a separate manual.

General Aspects of Interviewing the Elderly

We begin with an overall orientation to interviewing elderly respondents (drawn, in part, from other sources) to help you gain or increase appreciation of the special difficulties which may arise.

A questionnaire instrument is only as good as the interviewer's skills in using it, and good interviewing requires very special skills. We might add that a self administered questionnaire is only as good as its design - instructions, wording, graphics, etc.. Special efforts have gone into making this take-home instrument as easy to answer as possible. However, inevitably some people will not fill it out at all and most will miss something in one place or another. So good interviewing techniques must also be developed for situations where the self-administered forms become interviews, and for those sections where the protocol requires in-clinic review of take-home instruments.

Studies have shown that a respondent often remembers more about the interviewer and how the interview was conducted than about the topics covered during the interview. This finding emphasizes important aspects of interviewing: 1) an interviewer must be an understanding person capable of accepting what the respondent says without showing reactions of either approval or disapproval; the respondent must feel that her ideas are important, and that there are no right or wrong answers; 2) an interviewer must not influence the respondent by anything she says or does; and 3) an interviewer must help the respondent feel that the interview is an important contribution to research.

The Importance of Appropriate Participant Orientation:

The participant's advanced knowledge of the questionnaire will come from recruitment contacts with the researchers. It is important that participants know that filling out a questionnaire and being interviewed are essential requirements for being involved in the study. They should be told that they will be receiving forms in the mail that we want them to fill out and bring to their clinic visit. It is also a good idea to let them know a little about what is covered in the questionnaire and why we want to know about these things. (This topic will also be covered in the consent

form.)

Be prepared to answer such questions as: "What is the study about?", "How will it benefit me to be involved?", "Where did you get my name?", "How long will the interview take?", "Who else are you interviewing?". The most effective answers are brief, direct, and truthful. The potential respondent most often wants to establish your identity and the legitimacy of your call, and is rarely interested in any in-depth details of the study.

The more that participants know about what is expected of them, the more likely they are to fulfill those expectations. "An ounce of prevention..." In this vein, it is probably a good idea to: 1) have a phone number participants can call if they have problems understanding or completing the questionnaire, and 2) at a phone call to remind them about their appointment, ask if they were able to fill in the forms, if they had any difficulty, and if they have any questions. If they've had problems, try to assist them over the phone and encourage them to work on the forms prior to their visit. Reassure them that they can still be in the study, but try to fill out as much of the form as possible.

In a sense, our first "interview" with prospective participants is the initial phone contact. The tone you set in that interaction may carry over into all subsequent ones.

A potential respondent initially may not wish to participate. Listen carefully to her reasons. Be accepting, patient, calm and reassuring as you try to persuade her to cooperate. With interviewing experience comes assurance, and assurance helps overcome resistance. Getting cooperation from persons who are initially reluctant is important because their experience may be different from those of persons who cooperate readily.

Although you may try to change their minds, you must respect the wishes and privacy of persons who really do not want to be involved. Again, only experience and discussion with a supervisor can train the interviewer in when to accept a refusal and when to try to overcome resistance based on misinterpretation of the purpose.

Be straightforward about the time commitments involved -- both in completing take-home materials and in the complete clinic visit. Participants should not come expecting to rush through everything so they can make another appointment.

Conditions of Interviewing:

This is a difficult topic since due to time and personnel limitations we are planning to do some interviewing during bone density measurements. These conditions may be less than optimal. Nevertheless, strive to achieve the following conditions: strive for a private, quiet location. Both of you should be seated comfortably. Try to be in a position which will 1) allow you to have easy eye contact with the subject, 2) enable you to be heard without raising your voice, 3) avoid light glaring in either the subject's or your eyes, 4) permit you to write unobtrusively, and 5) not permit the subject to read the interview instrument. Always carry a clipboard with you for writing in case there is no table convenient on which to write.

All interviewing should be done in privacy. You cannot expect the same answers when a person speaks in front of others as when she speaks to you alone. Also, an interview conducted with others present will take longer to complete.

If others are present, make every effort to get them to leave the room. It is not impolite to indicate you were told to interview the subject alone. If the person does not leave, be pointed in directing your questions to the subject and in maintaining steady eye contact with the subject.

It is possible that an over-protective relative or a shy subject will not permit an interview alone. In these situations you must focus on the target respondent and discourage any participation from the other person. It may also be possible to enlist the help of the subject in asking the other person to permit the subject to answer for herself. If the other person continues to insist on intruding, firmly state you have been told to get the subject's answers only, but that you could talk with the other person briefly after you have finished the interview.

Special considerations for interviewing elderly persons:

Interviewing older persons is basically similar to interviewing persons of any age. There is considerable variation among older people just as there is among persons of other ages. Most of the older persons you will interview will be able to respond to all questions.

Many older persons have had little experience being interviewed. A major task of the interviewer is to clarify what is expected of a respondent and to guide her comfortably through the interview. Most people are pleased to be chosen as respondents and to know that their answers may contribute to solving the problems of other people. Your personality and ability to put the respondent at ease are usually all that are needed for a successful interview.

Ask all questions, but most particularly those of a personal nature such as age and education in a straightforward, matter-of-fact tone of voice; accept all answers without showing surprise, approval or disapproval.

An interview is a two-way street: the subject must understand you and you must understand her. Speak clearly and slowly. Speaking quickly will not speed up an interview but rather, it may confuse the respondent and actually slow up the interview. Always listen very carefully.

At times you may confront some difficulties in interviewing. Some suggestions on how to handle special situations follow:

A respondent with difficulty hearing: Sit close enough to the subject so that you do not have to shout. For some people the more you raise your voice, the more distorted the voice sounds to the respondent and the harder you are to hear. It is possible to let the respondent read the questions or to let the subject read a blank form while you ask the questions, rather than lose the interview.

A respondent with limited vision: If the subject is so visually impaired that she cannot read the materials you hand her, read them to her.

A respondent with difficulty understanding a question: If a subject does not understand a question, repeat the question clearly, slowly, and without raising your voice, possibly changing the emphasis of the words or the tone of your voice. Under no circumstances are you to reword, explain, or interpret the question. Encourage the subject to do the best she can. If she still does not understand, treat as missing data and move on.

A very talkative respondent: Frequently you will encounter a subject who wants to talk at much length about herself or in a social manner, or one who is not able or willing to keep to the focus of the individual questions. While being accepting of the person and her needs, do not hesitate to interrupt the subject gently but firmly, saying something like, "I don't want to take up too much of your time, so let me ask you now: (repeat question)". It also helps to lose eye contact with the subject, look down at the interview instrument, then look up and say, "Perhaps you can tell me more about that when we are finished. Now I'd like to ask you...", "Isn't that interesting. Now let me ask you this...", as a last resort, "Excuse me, but let's get back to the question: (repeat question)".

A respondent who becomes upset: Very occasionally a subject will become upset or cry during the interview. If this happens, decide where your responsibility as a person begins. There are no hard and fast rules. Generally, you should be sympathetic without becoming involved. Do not routinely probe as to why the subject is upset or crying. In some cases it may be helpful to divert the subject's attention from her distress back to the interview. In fact, it may sometimes be very reassuring to the person for you simply to say, in a matter-of-fact voice, "Now let me ask you... (next question)". In others, this may have an adverse effect. When the subject is able, return to the interview. If the interview is completed and the subject is still upset, don't leave her until she has regained composure. If necessary socialize to help accomplish this.

It is, of course, imperative that you not try to be a psychotherapist. It is one thing to be an understanding listener who conveys human sympathy but quite another to participate actively in drawing out material relating to personal problems. The latter should not be done. Each center should establish a channel through which a referral for counseling or emergency help might be obtained if necessary. Unless it is a matter of risk to the life of a person, however, no such referral can be made without the prior permission of the interviewee.

A respondent who is unable to handle the interview: In some very few cases it will be apparent that the subject is not physically, intellectually and/or emotionally capable of participating in the interview, although she has agreed to do so. Judgement to discontinue the interview is to be made by you based not upon incorrect answers to any single or group of factual or other questions, but upon a trend indicating gross cognitive incompetence, inability to comprehend the questions, inappropriate answers or grossly contradictory answers. These would indicate the instrument will not obtain meaningful information about the respondent and is probably a severe burden to her. Be alert, however, to distinguish the subject who is not oriented as to time, place etc., yet can give good information about her life, in which case the interview can be conducted.

General Guidelines for Administration

Format:

The questionnaires consists of a take-home, self-administered questionnaire (SAQ), and a clinic administered questionnaire (SAQ). The SAQ is divided into two parts: 1) Medications, and 2) a Health and Personal History. Each part of the take-home has a separate set of instructions. The two parts will be bound together in a single booklet.

The clinic interview has three parts: 1) a medications chart which guides you through a thorough review of medications history based on the take-home questions about medication use and pill bottles, 2) procedures for review of various sections of the Health and Personal History, and 3) questions about smoking, alcohol, functional disability, physical activity and a two instruments for assessing cognitive function.

Take-home and interviewer administered questions have similar formats to ease transition between the two. The take-home sections have also been designed to be administered in cases where the participant has not filled out the forms at home.

Interviewer instructions in the administered sections are printed in capital letters and sometimes set off in brackets. They are not to be read to the respondent.

Stem or primary questions (those asked of all respondents) are numbered and out at the left margin. Conditional questions (those asked of some respondents) are enclosed in boxes and set off to the right. Arrows from the answer boxes for stem questions point the way to the conditional or

to the next question.

Precoded Answers: Most of the questions have precoded answer categories (Yes, No, and Don't know are the most frequent). The box corresponding to the respondent's answer should be marked with an X. Only one box is marked per question, unless the instructions state otherwise.

Open-ended questions: The questionnaire contains only a few items that are not precoded. If an answer does not seem meaningful or complete, you can encourage the subject to expand or elaborate her answer by using the technique called "probing". Probing must be nondirective, i.e., a question or statement by the interviewer that does not suggest an answer, but does stimulate further communication. All of us use nondirective probes every day when we say: "What do you mean?", "Tell me about the...?", "In what way?", "Yes?", "Why?", "I'd like to hear more about that...", "Uh-huh...", or "I see...".

Change of answer: Never erase an answer. Since we suggest you work in ink that would be difficult to do. If the respondent changes her mind while you are recording the answer to an open-ended question, just continue recording verbatim. If the respondent changes her answer to a precoded question or you make a recording error, put a slash through the code that has been incorrectly marked and mark the correct one.

If at a later part of the interview the subject mentions something that adds to or contradicts an earlier response (i.e., a hospitalization is mentioned which was not reported earlier), change omissions the subjects draws attention to i.e., "Oh, I forgot to tell you about being in the hospital for cataracts." Probe to correct for obvious contradictions e.g., "I must have gotten something wrong you just said -- but I thought you said previously that..."

Other (SPECIFY) responses: Some questions combine the features of both precoded close-ended and open-ended questions. In addition to the precoded answer categories, provision is made to record an answer that does not fit into any of the precoded categories: "Other (SPECIFY)". The word "SPECIFY" or "DESCRIBE", etc. written in capital letters and enclosed in parenthesis, is an instruction to mark the code for "Other" and to write in the verbatim handwritten response.

Introductions: Sometimes an introductory sentence is used to ease into a question and maintain the flow of the questionnaire. Read the introduction to the subject as it is written.

Alternative wording: Some questions offer options of wording to best fit the respondent's circumstances. Alternative phrasings are set off in parentheses and separated by slashes i.e., "How many pills do you take per (day/week/month)."

Response cards: It is often easier for a person to answer a multiple choice question if the choices are on a "card", a card that is handed to the respondent listing the response options. The administered alcohol and physical activity sections have response cards.

Editing: All answers must be obtained and recorded at the time of the interview...nothing is to be written in afterwards. Check the questionnaire to see that all questions are answered completely while you are in the presence of the respondent.

Account for every question: All questions are to be asked in the order in which they appear and exactly as they are printed. Ask every question unless there is a SKIP instruction. Never assume you know the answer. Record an answer for every question even if it is to indicate the subject refused to answer (REFUSED), said she didn't know (DK), or gave no answer (NR).

Be sure the subject's answer fits into a response category: If the subject replies in an ambiguous way, like "sometimes yes, sometimes no", to help her resolve this to a single answer, you might ask, "If you had to choose, is it usually yes or no?"

Do not question the validity of the subject's responses: Occasionally you may have strong questions about a subject's responses. For instance, in the ADL section, in rare instances a subject reports that she is capable of doing IADL tasks though she may be grossly impaired. Again, write in the subject's actual response and put a "?" in the margin. This will remind you to comment on this apparently invalid response in your qualitative notes on the back sheet.

Special considerations for "frequency" questions:

- a) Clarify the time span: Many questions ask about behavior "during the past twelve months" or "during the past year". From time to time reemphasize "past 12 months". It is usually a good idea to restate the time frame as "since this time last (May)".
- b) Obtain specific frequency responses: Frequency questions are generally precoded to translate unstructured answers into categories. People don't usually think about the frequency of their behavior and therefore, some subjects have difficulty in answering. Repeating the question, stressing "about how often...", sometimes helps. If the subject answers in a very general way, like "whenever I have time" or "pretty often", ask about how often this is on the average. If the subject still cannot answer, read the categories and allow her to choose the most appropriate one.

Responses should apply to the subject at the time of the interview: Some questions are meant to assess the subject as she is at the moment, much like a snapshot of a person. If a subject is currently doing things differently than she usually does, decide for yourself whether the current situation is very temporary for indisputable reasons. If the subject's situation may or may not be temporary, code according to current functioning. (E.g., if the subject is receiving help with IADL because she is incapacitated with a broken hip, rate as "with help", because one cannot determine how long the condition will continue or if she will resume her former level of functioning.)

HOW TO GET ADEQUATE ANSWERS:

- A. Ask the questions exactly as worded and in the same order as they appear in the questionnaire. Minor changes in wording can completely change the meaning of a question. Unless each interviewer asks the questions exactly as shown, the answers may be meaningless.
- B. Don't try to explain the question. Be neutral. As indicated earlier, if a respondent does not seem to understand a question, repeat the question slowly and clearly. Give the respondent time to think about the question. Unless you have other information about handling specific questions, the only acceptable answer for a respondent who wants to know what a question means is "Whatever it means to you." Never explain the meaning or purpose of a question unless the interviewer instructions authorize you to do so.
- C. Don't define terms used in questions. Some respondents may ask you what we mean by a word used in a question. Leave the matter of definition to the respondent, except where the written instructions authorize a definition or alternative wording. Instead of offering your own definition (while another interviewer is suggesting a completely different definition to someone else), simply say "Whatever you think _____ means" or "Just whatever it means to you" or "However you use the term _____."

One exception to this rule is that for certain factual questions you should watch for inconsistencies and try to get the correct fact.

- D. Don't leave a question until you have an adequate answer or have determined that a respondent can't give a clearer answer.
- E. Don't accept a "don't know" without probing at least once. A respondent may answer a question by saying "I don't know" when what she really means is she has never thought about it or needs time to think. Give her a chance to collect her thoughts and express them. With skillful help, with encouragement and time, an inarticulate respondent may express herself. In general, if a subject can make a judgement in favor of a response other than "don't know", the usefulness of the data is greatly increased.
- F. Use neutral probes that do not suggest answers. Probes are needed to obtain more complete and detailed answers. All probes must be non-directive. That is, your probe must not suggest any particular answer to the respondent. Probes should be used whenever the respondent is hesitant in answering the questions; when he seems to have trouble expressing himself; when he seems to shy to speak at length; whenever there is any reason for the interviewer to think that the respondent has not given a complete report of his thinking; and finally, reassuring probes are needed when a respondent seems to lack confidence.

Many interviewers forget to use two of the most effective neutral probes: (1) silence and (2) repeating the original question.

- (1) The value of silence in an interview cannot be exaggerated. In today's hectic world, many people -- including interviewers -- react to silence as a vacuum which nature abhors and must be filled with constant chatter. The interviewer who can wait patiently and quietly (with an interested expression on his or her face) will soon find that 15 seconds of silence is more than most respondents can take, and the respondent will often expand or clarify a previously inadequate answer if you simply shut up and wait.
- (2) Repeating the question is another safe way of probing. Be sure to repeat only the question as stated in the questionnaire. This is particularly useful when the respondent answers a question irrelevantly. Without pointing out that the first answer was irrelevant, simply say "Isn't that interesting. And now let me ask you this (AND REPEAT THE QUESTION)". In some cases you must remind the respondent of your frame of reference when you repeat a question. For example, if you ask "How long have you lived in the Bay Area?" a respondent might say "I've lived in California all my life. You know, there really aren't many native Californians my age." Instead of coldly ignoring what the respondent has said, acknowledge it and then bring the respondent back to the subject by repeating the question. In the above example, you might say "Is that so! And how long have you lived in the Bay Area?"

Other neutral probes that you will find useful are:

How do you mean?

In what way?

Please give me an example. OR For example? OR For instance?

Please explain that a little.

How are you using the term, _____?

How come?

Tell me more about that.

What makes you feel that way?

I just want your impression.

I just want your opinion.

Anything at all -- even little things?

What else can you tell me about that?

(REPEAT THE CODE CATEGORIES IN A PRECODED QUESTION)

(REPEAT THE AMBIGUOUS TERM ON A RISING INFLECTION WHICH SUGGESTS A QUESTION)

If you had to choose, which would you say?

Generally speaking, we avoid some neutral probes in favor of others:

Instead of "Anything else?" which invites a "no," you'll find "What else?" or "What else can you tell me about that?" is more likely to elicit more answers.

Instead of "Why?" which some people interpret as critical, you'll find "What makes you feel that way?" or "I'd be interested in your reasons" accomplishes the same purpose and is less likely to be threatening.

Some of the kinds of questions used in ordinary conversation must be avoided because they suggest answers:

Don't ask: "Do you mean A or B" (unless you have asked a precoded question). This is not neutral because it suggests two possible answers and there may be others which do not occur to the interviewer but would occur to the respondent if she were left to her own devices.

Don't ask: "Do you mean (SUCH AND SUCH)?" because many people tend to say "yes" to any suggestion either because it's easy or because they think it's the right answer.

Don't ask: "Then you feel (SUCH AND SUCH)?" Even though you're trying to summarize what the respondent has already said, you may be placing the emphasis on the wrong part of her answer.

- G. Watch your tone of voice (and facial expressions in face-to-face interviewing). How you ask a question or probe can be just as important as the wording of the question. Be careful that a tone of censure or criticism does not creep into your voice. "What makes you feel that way?" is, for example, usually a good way to get people to explain their reasons, but "What makes you feel THAT way?" may suggest that only the insane would hold such a view. Similarly, your face may give you away.

- H. Watch for vague answers. Some respondents find it hard to verbalize and may have difficulty expressing their ideas. When people take refuge in vague generalities, probe for examples to help them clarify their ideas.
- I. Guard against ambiguous answers. Certain terms may mean very different things to two or more people. Always ask yourself whether you are sure you know what a respondent meant by an answer and whether another interviewer would have interpreted a given answer in exactly the same way. If anyone uses terms or phrases which could be interpreted differently by different people, you must go back to the ambiguous phrases and ask her "How are you using the term _____?" or "What do you have in mind when you say _____?". While this is a particular problem in free-answer questions, some respondents will give vague answers to precoded questions, which must be probed.
- J. Avoid "depends" or "qualified" answers. Never accept a "depends" or "qualified" answer the first time it is offered as a response to any question. Respondents often use phrases such as "well, that depends", "yes, but...", "I really see both sides of that question", etc.. When a respondent gives a qualified answer, we advise one of the following probes:
- Repeat the question (unless the response was such that it will sound as though you weren't listening).
 - Preface the question with a phrase like "well, in general," "on the whole," or "taking everything into consideration".
 - Remind the respondent that we want to know which statement code comes closest to the respondent's views; use an introductory phrase such as "Well if you had to choose" or "Even though you're somewhere in the middle, which way do you lean?" and repeat the question.
- Occasionally a respondent will answer with a genuine qualified or depends answer, which cannot be pushed into an existing code. If the respondent insists upon answering in qualified terms after you have sufficiently probed, simply record verbatim his entire response.
- K. Clarify one response before asking for more. "What else?" is an excellent probe for getting people to offer additional ideas on a subject. But before asking for other answers, use clarifying probes to encourage respondents to explain what they have already said. If you don't clear up one response before asking for more, you'll wind up with a series of vague or ambiguous responses which are uncodable.
- L. Make your probe consistent with the purpose of the question. Knowing a few neutral probes and asking them correctly is not enough. You must choose a probe that is appropriate for the particular kind of inadequate answer given. As we noted above, there is no point in probing "what else?" if the respondent's previous answers were vague. Similarly, "Tell me more" may get you farther and farther away from your goal of getting the respondent to choose one of several possible precodes, and "If you had to choose..." would be a better candidate. If the respondent has answered fully but used an ambiguous term, you will want her to clarify that term by using a probe like "How are you using the term _____?" rather than asking her to explain, which might encourage her to explain things that are clear without clarifying the ambiguous term. In the same way, a person who lacks confidence will not gain it simply because you repeat a question, whereas "I just want your opinion" or "What's your impression?" will be more likely to encourage him to answer. Some respondents who are unsure of themselves may be more likely to respond to "Tell me any problems that occur to you -- even little things" when they are thus

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reassured that they need not restrict their answers to earth-shaking ideas.
M. When in doubt as to what is needed, get more rather than less than may be needed. If you get more data than we need, we can ignore it. But if you get less than needed, we must either return to the respondent or code "no answer". In order to avoid the unnecessary loss of important data, bear in mind the following rules:

- When in doubt whether to ask a question, ask it.
- When in doubt whether to probe for greater depth, probe.
- When in doubt whether to record, record.
- When in doubt whether to enter an explanatory, parenthetical note, enter it.