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TAILORING TRADITIONAL INTERVIEWING TECHNIQUES FOR QUALITATIVE RESEARCH WITH SERIOUSLY ILL PATIENTS ABOUT THE END-OF-LIFE: A PRIMER[*]

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Abstract

Conducting qualitative interviews with seriously ill individuals about end-of-life issues is challenging for interviewers seeking to understand the problems, processes, and experiences individuals undergo when faced with death and dying. Although all qualitative interviewers face issues of building trust and obtaining answers to their research questions, these issues are exacerbated for interviewers of end-of-life issues due to the challenges of debilitated participants, sensitive subject matter, and heightened emotionalism. The purpose of this article is to offer field-tested techniques to tailor basic interviewing practices for discussions of end-of-life issues with seriously ill individuals. Use of tailored techniques facilitates the comfort of both interviewer and participant and enhances the probability of obtaining complete and accurate data, which in turn can improve the effectiveness of subsequent programs, policies, and clinical practice based on research findings.

INTRODUCTION

Conducting qualitative interviews with seriously ill individuals about end-of-life issues is challenging for interviewers seeking to understand the problems, processes, and experiences individuals undergo when faced with death and dying. Although qualitative interviewers in all fields face issues of developing rapport, building trust, and obtaining answers to their research questions, these issues are exacerbated for interviewers of end-of-life issues because of the challenges of debilitated participants, sensitive subject matter, and the increased potential for discomfort to both the interviewer and participants. Additionally, there is heightened anxiety and emotionalism that surrounds interviews with dying patients who are asked to discuss their impending deaths (Borreani, Brunelli, Miccinesi, Morino, Piazza, Piva, et al., 2008; Daly & Rosenfeld, 2003; Grumann & Speigel, 2003) that may not be as present during interviews with other patient populations. Due to these difficulties, data on end-of-life issues are not often obtained firsthand from patient informants, but rather by

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proxy from patients' caregivers. Proxy data are not as reliable or valid as data obtained directly from patients because the data represent the proxy's subjective opinion of the patient's experience (Tang & McCorkle, 2002a). Collecting qualitative data directly from seriously ill patients is preferable, and possible with some adjustment to customary interviewing techniques.

The purpose of this article is to offer field-tested techniques to tailor basic interviewing practices for discussions of end-of-life issues with seriously ill individuals. While several seminal efforts have demonstrated the value of qualitative methods in studies of death and dying (Emanuel, Fairclough, Wolfe, & Emanuel, 2004; Glaser & Strauss, 1965, 1967; Koenig, Back, & Crawley, 2003), there remains little guidance for the qualitative interviewer on how to conduct interviews with seriously ill individuals about end-of-life issues. Traditional interviewing techniques offer some guidance; however, the usual qualitative interviewing techniques may require modification and refinement when employed in studies with seriously ill participants about end-of-life issues. For example, researchers have reported on optimal content and phrasing of information during interviews with terminally ill patients (Clayton, Butow, Arnold, & Tattersall, 2005), and appropriate timing for data collection (Tang & McCorkle, 2002b).

Although research with seriously ill participants may seem daunting, researchers have found that once the topic is broached, patients are eager to share their thoughts and experiences about the end-of-life and want the opportunity to have their voices heard (Emanuel et al., 2004; McIlfatrick, Sullivan, & McKenna, 2006; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000). However, seriously ill participants are at different levels of understanding and acceptance of their prognoses, which may change over time. For example, participants who are appropriate for hospice but are pursuing aggressive treatment may not have even begun to think in terms of the end-of-life. Without familiarity with the participant, the interviewer does not have the knowledge of where the patient is in this process. Presumably, participants who agree to be interviewed about the end of life are comfortable with the topic; however, interviews must be approached with regard for participants' changing ability to discuss their end-of-life concerns.

Use of techniques tailored for this purpose facilitates the comfort of both interviewer and participant and enhances the probability of obtaining complete and accurate data. Twelve techniques for conducting qualitative interviews with seriously ill individuals about end-of-life issues (Table 1) are discussed below.

TECHNIQUE #1

Find a Recruiter Who Knows the Participant Pool

When recruiting participants, it is useful to gain the assistance of someone whom potential participants know and trust, such as a clinic nurse or social worker (Fetterman, 1989). Having such a person first approach potential participants about participation will help make participants more amenable to meeting the interviewer to discuss the study further. Additionally, being approached initially by someone they know may make participants more apt to be open and emotionally ready to participate, and may help gain the support of family caregivers who are often protective of their loved ones, particularly at the end of life. If interviews are being conducted in an institutional setting such as a hospital, nursing home, or hospice, having a staff member introduce the study to other staff members can also assist with gaining access to patient participants (McHale-Wiegand, Norton, & Baggs, 2008).

TECHNIQUE #2

Take Adequate Time with Obtaining Informed Consent

Planning for adequate time during the informed consent process is important for building rapport and trust. This is often the first formal exchange that the interviewer has with the participant, and the quality of the interaction will set the tone for the interview. Especially in the area of end-of-life, which to some individuals may be private and/or difficult to discuss, the consent process can be intimidating and fear-invoking. In addition, many potential participants who are seriously ill may not read the informed consent form, but rather rely on the interviewer's verbal description of the study to decide if they wish to participate. The interviewer may assume that the verbal description is all the information potential participants will get, and sufficient time should be allowed for this task (Flory & Emanuel, 2004). It is likewise important to take the time to be sure potential participants understand the purpose of the study and how much they can contribute to it. Many participants view the benefit of helping others in their position in the future as very valuable (Chochinov, 2007), and the interviewer can note this benefit.

During the initial consent interaction, the interviewer should explain the types of questions that will be asked in the interview so participants will know what to expect ahead of time. This technique will help minimize the chance that the participant will be surprised or feel awkward about the questions. This process is an opportunity to build trust and to ensure that the individual is informed and emotionally ready to be interviewed. It is unlikely that useful data will be obtained from a reluctant participant. Extended interviewer-participant discussion of a research study is perhaps the most effective way of increasing participants' understanding of the study and their role in it (Flory & Emanuel, 2004).

If possible, it is helpful to obtain the consent of potential participants before the interview, so that the "business" part of the study is separate from data collection. The consenting process can be off-putting and awkward for some, so separation from the interview itself eliminates introduction of any negative feelings into the interview. Additionally, separation of the consent process from the interview helps both the interviewer and the participant to be fresh for the interview and will allow more time to collect data.

Although separation of the consenting process and the interview is ideal, the interviewer does not always have this luxury when interviewing seriously ill patients. The interviewer should have the mindset and flexibility to conduct the interview whenever the opportunity presents itself (Kirchhoff & Kehl, 2008). Although an interview date may be scheduled, the participant may unexpectedly not feel well enough to be interviewed at the appointed time, or unavoidable interruptions may occur, especially if the patient is in the hospital or inpatient hospice (McHale-Wiegand et al., 2008). Therefore, keeping research materials (e.g., consent forms, recorder, interview questions) on hand enables the interviewer to be prepared to conduct an interview on short notice.

TECHNIQUE #3

Foster a Sense of Trust and Safety from the Outset of the Interview

Development of rapport is extremely important in any interview, but establishment of trust is crucial when the subject matter of the interview is sensitive and may cause an emotional reaction in the participant (Wright & Flemons, 2002). The participant is being asked to share with a stranger very intimate, potentially painful information that he or she may not have discussed with anyone before, or even been aware of. Because interviews can produce strong feelings and self-disclosure that participants may later regret, researchers must be mindful of participants' wellbeing (Hudson, 2003; May, 1991). Participants can answer questions and seem to engage even when rapport is not established, but the depth of the data and the feeling that it is safe to delve deeper can be enhanced if trust and safety have been developed.

One way to establish rapport with seriously ill participants is to acknowledge their situation. The interviewer can show the participants that the interviewer cares about them and is sensitive to what the participant is experiencing (Benjamin, 1981). For example, if the participant has just been admitted to an inpatient hospice, the interviewer might mention this at the outset of the interview: “I understand that you just arrived here 2 days ago. How have you been adjusting?” If a hospitalized patient asks for a cup of ice chips or an extra blanket, this creates an opportunity for the interviewer to demonstrate caring, as well as to provide a needed service. If a clinician or other visitor comes into the room or if the phone rings, the interviewer should ask if the participant would like him or her to step out. Participants’ privacy should of course be respected. Additionally, medical care or visitors often take precedence over the study.

If possible, the interviewer should choose an interview environment that is quiet, private, and comfortable, with as few distractions as possible (Benjamin, 1981). Doing so will increase the understanding that the interview is confidential and that it is a safe place to talk. The participant may speak in a low voice or tire easily, and the environment should not limit the hearing of what is said or compromise the quality of the recording if the interview is being audiotaped.

Fostering a sense of trust and safety can also be facilitated by the interview format. In some cases, it may seem best to conduct a group interview. Use of focus groups with vulnerable populations, as distinct from individual interviews, has been debated (Hudson, 2003; Owen, 2001; Seymour, Bellamy, Gott, Ahmedzai, & Clark, 2002). For the purpose of interviewing seriously ill individuals about death and dying, focus groups may not be the best method for obtaining information for several reasons. First, end-of-life matters are very personal, and many individuals prefer to only speak about the issues in private under the condition of confidentiality; therefore, recruitment may be difficult. Second, those who agree to participate may still feel inhibited by the presence of others, and it is typically more difficult to establish rapport with a group than with an individual, again limiting the potential quality of the data (Morgan, 1997). Third, some individuals may not be willing or able to talk about the topics others raise in focus groups. As a result, some individuals may become upset when hearing others talk, making it difficult to continue the group.

If the interviewer feels strongly about use of focus group methodology, we offer two guidelines for consideration. First, the topic of the focus group may be the most important determinant of whether or not focus group methodology is appropriate. For example, the topic of how seriously ill individuals choose a health care proxy is less emotional than the topic of terminal patients’ expectations of the dying process. Participants may be able to engage well in a group discussion of the former, whereas the latter may be too personal and emotional to explore in a group setting. The interviewer must use discretion in deciding if a topic lends itself to group discussion. Second, it may be helpful to pre-screen potential participants to see how similar or dissimilar they are before the group. While the merits of homogenous or heterogenous focus groups are debated (Brown, 1999), focus groups in this area of research may particularly benefit from inclusion of more similar members. For example, members of an established, long-term support group may feel more comfortable with each other than would a group of strangers.

TECHNIQUE #4

Develop a Sense of the Participant

A major challenge of conducting interviews about the end-of-life is being able to advance the interview to the point where the most sensitive topics (e.g., prognosis, the dying process) can be discussed with a satisfactory level of comfort for the interviewer and the participant. A first step in doing so is to gain a sense of the participant: What is the participant's story? What does the participant understand about his or her condition? How open or comfortable is the participant with discussing his or her situation? In some cases, the interviewer may be able to obtain some preliminary information about the participant from the referral source if permitted under the Health Insurance Portability and Accountability Act (HIPAA). The interviewer can also gain a sense of the participant through informal pre-interview talk as the interviewer and participant are getting settled.

One of the most productive methods of getting to know the participant is to begin the interview with a broad, open-ended question (Benjamin, 1981) such as, "Can you tell me briefly what has happened since you were first diagnosed?" The interviewer can then observe how detailed the response is, whether or not it has emotional content, and what topics are emphasized (Reissman, 1993). Follow up questions can then be posed accordingly. Beginning with broad, non-threatening questions can also help build rapport.

TECHNIQUE #5

Meet the Participant Where He or She Is

The interviewer should assess how willing and ready the participant is to be interviewed both in terms of time and content. Regarding time, the interviewer should generally plan for an approximate 45-minute interview, which is shorter than the traditional open-ended interview (Patton, 2001; Weiss, 1994), but appropriate for participants with serious illnesses. Depending on the population under study, interview length may need to be even briefer. The interviewer should let the participant know how much time he or she can expect to spend in the interview in advance of starting. Even if this was mentioned in the consent process, the interviewer can remind the participant at the outset of the interview, so the participant knows what to expect and can feel more comfortable. At the time of the interview, the interviewer should periodically gauge how the participant is doing by watching for signs of fatigue or discomfort, or by asking if he or she is comfortable continuing. If possible, conducting the interview with a break in the middle or in more than one sitting may be helpful to meet participants' needs, and may increase the likelihood of getting trustworthy and rich data (Weiss, 1994).

However participants present, the interviewer should aim to meet participants where they are, even if unexpected surprises occur. For example, after asking a certain question in a few different ways without getting a response, the interviewer can assume that the participant is not comfortable discussing that topic or line of inquiry. Participants may not be explicit with the interviewer about their level of discomfort, so it is useful to pay attention to nonverbal and verbal cues, and to be satisfied with the extent to which the participant invites the interviewer into his or her world.

As expected, every participant reacts differently to an interview. Participants may cry, or may be quite verbal for a time and then seem to withdraw a bit. It may be relevant to the research to ask about changes in demeanor—e.g., "You seem not to want to talk about that hospital stay." Even if participants' demeanor is not pertinent to the research, it is important to be supportive of participants as their perceptions and feelings are revealed (McHale-Wiegand et al., 2008).

TECHNIQUE #6

Start with Safer Ground and Peel Back the Layers

When progressing toward the heart of the interview where the most sensitive questions are posed, it is useful to take some time initially to discuss safer ground, that is, areas that the participant seems more comfortable discussing, or over which the participant feels more control. In doing so, the interviewer can slowly peel back the layers of the participant's story and the meaning or value attached to each layer. Eventually the hardest questions will be reached; for example, what the participant thinks his or her death will be like for the family. As in a clinical interview, researchers must be sensitive to participants' readiness to discuss death (Wenrich, Curtis, Shannon, Carline, Ambrozy, & Ramsey, 2001). This technique of asking less sensitive questions, then more sensitive questions, and then less sensitive questions again can help minimize patient burden (McHale-Wiegand et al., 2008). Proceeding in this manner will also make the interview easier for the interviewer, as many of these questions are sometimes as difficult to ask as they are to answer.

TECHNIQUE #7

Go Slowly

It is helpful to move slowly through the interview questions, so as not to overwhelm the participant. The interviewer should try to address one topic at a time, and not recycle through the same topic. Becoming very familiar with or memorizing interview questions can assist in smooth coverage of all research topics.

Just as a slow immersion into the interview is necessary, so is a slow progression out. It is considerate to guide the participant out of the interview in a manner that makes him or her feel safe, heard, and not foolish for having revealed personal information. This can be accomplished by acknowledging what the participant has gone though, both in the experience itself and the sharing of the experience. Thanking the participant for this sharing is also valuable. For example, “You have really been through a lot, Sandy. Thank you so much for allowing me to hear your story.” The interviewer should watch the clock so that there is enough time for this resurfacing process (Benjamin, 1981). If necessary, the interviewer can ask the participant if a second contact is acceptable, and can inform the participant that he or she may also contact the interviewer with any additional information or thoughts (Briller, Schim, Meert, & Thurston, 2007–2008).

TECHNIQUE #8

Go Where the Participant Goes

Just as the interviewer wishes participants to reply to research questions, the interviewer should be prepared to listen and go where they go. Such flexibility respects the individual needs and abilities of participants to discuss various aspects of their experience and is a key interview practice (Rose, 1994). Although some participants may seem to take a tangent, they may actually be making connections between constructs that have not yet occurred to the interviewer. Being alert and open to participants' responses will help the interviewer refine the research questions for subsequent interviews, and may ultimately help the interviewer to better comprehend the phenomenon under study.

In the same way that the interviewer wishes to prepare the participant for the most sensitive subject matter, the interviewer likewise must be prepared. The interviewer should consider before the interview the direction the research questions may take, even if it is not the intent. It is useful for the interviewer to think about possible reactions to participants' comments in the event that they go in unexpected directions. The novice interviewer in particular may wish to practice asking the difficult questions so that the interviewer will be able to pose them to the participant in a non-value-laden or emotion-laden manner.

TECHNIQUE #9

Redirect the Participant Appropriately

Sometimes when a question is posed, participants do not respond to this question, but rather begin speaking about another topic. This often occurs because participants have something pressing on their minds that they need to share, regardless of the question asked. As noted above, it is useful to let the participant go where they want to go, but in order to have research questions answered, some structure must be imposed (Rose, 1994). We recommend that the interviewer first try subtle ways of redirecting the interview, perhaps by acknowledging what the participant has said, and then rerouting the conversation. As an illustration:

> I: So what was it like for you to make the decision to go to hospice?
>
> R: Hospice was a Godsend. My family could visit and they were able to sleep over if they wanted so they could spend more time with me, and really they wanted one person to be with me at all times.
>
> I: So you liked that your family could spend a lot of time with you at hospice. Let’s take a step back in time to before you got to hospice. How was it for you to decide to go there?

With participants who persist with one line of thought, the interviewer can consider why that subject is so important to them and ask about it. For example: “You seem to feel very strongly about your family being able to stay with you. Can you tell me more about that?” Finally, for participants who ramble, a more explicit redirection may be needed. For example: “I appreciate your telling me about your family. What I am interested in hearing about now is how you decided to go to hospice.” Since the interviewer does not want to unsettle participants or make them feel like they have not answered the questions “satisfactorily,” the interviewer should try not to use explicit redirection more than two to three times over the course of a 45- to 60-minute interview (Weiss, 1994). It is useful to practice different ways of asking a question so that the desired data may be obtained (Rose, 1994) and participants’ needs are respected.

TECHNIQUE #10

End in a Way that Allows the Participant to Reflect and Regroup

The interviewer should end the interview with a broad question such as: “Is there anything else you want to add to help us understand your experience with completing your advance directive?” The participant may come up with data that were never considered, or that the interviewer never thought the participant would want to talk about. It is often the case in interviewing that the participant “spills” as soon as they perceive the “formal” part of the interview to be over, or when the recorder is switched off. This may be particularly so in end-of-life interviewing because, for some participants, if they do not relay their story to the interviewer, they may not relay it to anyone, which can leave them feeling frustrated, and leave valuable data missed. It may also help to conclude the interview by asking participants what the interview experience was like for them. This technique may help them review the experience, reassure themselves that they are okay, and feel a sense of accomplishment. Just as the interview is opened with “safe” subjects, it should also be closed with safe subjects to support the participant’s emotional health. For the interviewer, feedback about the interview questions and review of the transcript may help refine content areas or procedures.

TECHNIQUE #11

Wear Only Your Interviewer Hat

It is easy for the interviewer to feel the impetus to share personal experiences in sympathy, or to educate or counsel participants as the interview progresses, yet the interviewer must wear only the interviewer hat to ensure the integrity of the data. Such activities are not usually useful for the participant or for the purposes of the interview. Sharing personal experiences can blur the interviewer’s role as an interviewer with that of a friend or a therapist (DeVaus, 2001; Rose, 1994). Participants will be much more trusting in the long run if they realize the interviewer only wears the interviewer hat because this makes the interviewer’s role clear.

We feel it is not the interviewer’s place to offer clinical information or advice usually provided by a participant’s health professional. Nor is it appropriate for the interviewer to discuss interview content with the participant’s health professional or family member, as this would be a breach of confidentiality. This situation may be awkward or disturbing for the interviewer, especially if a participant expresses a clear misunderstanding about something, e.g., the disease process or treatment options. These feelings can be mitigated. It is appropriate for the interviewer to refer participants to their health professional should they express confusion about their health or healthcare. In addition, the interviewer may offer to relay a participant’s questions or concerns to a desired individual with the participant’s permission (McHale-Wiegand et al., 2008).

It is, of course, appropriate for researchers to be available to participants if they become upset by offering a tissue or sitting quietly with them. The interviewer can also suggest additional social or psychological assistance to participants if indicated (Jones & Lyons, 2003). It is useful to obtain agreement of a therapist who is willing to see distressed participants, if necessary, at the outset of the research study (Cassaret, 2005).

TECHNIQUE #12

Interviewer Reflection

Conducting interviews with seriously ill individuals can be emotionally taxing for the interviewer (Jones & Lyons, 2003; Wright & Flemons, 2002). The subject matter can be very uplifting, but also very tragic. Self-care when conducting interviews with seriously ill people is very important, both for the health of the interviewer and the quality of the data. There are several strategies that promote interviewer reflection. One is for the interviewer to continually gauge the depth of his or her involvement in the interview. It is helpful to the interviewer’s own health to be present with participants and join them in their world temporarily, but not get too involved. This balance is difficult to achieve, especially when rapport has been established or the interviewer particularly identifies with a participant. It can also be difficult to break the intimacy that develops with a participant once the interview is concluded. The ideal practice is to be able to be present enough to understand the participant’s world, but at the same time distant enough to complete the interview agenda, effectively delve for richer data, and meet the responsibilities to the participant.

Another strategy is for the interviewer to be alert to personal feelings and reactions to seriously ill people. Being familiar with personal experiences with serious illness and death will help reduce the likelihood of interviewer burnout or unanticipated reactions during an interview. Conducting a personal debriefing following an interview can help the interviewer process any feelings brought up by the interview (Rose, 1994). Debriefing is probably best done with a co-investigator so the interviewer may speak freely about participants without compromising confidentiality. A more formal way to debrief is to conduct an “interviewer interview," where the interviewer is interviewed about the participant interview to process the experience. This activity is best done as soon as possible following the participant interview. In addition to supporting the interviewer's emotional health, the interviewer interview can be audiotaped and utilized as data. A third strategy is to leave enough time between interviews so as not to become overwhelmed (Cook & Bosley, 1995). It is also useful to conduct this research at the same time or interspaced with other less taxing research efforts. Finally, role playing or conducting practice interviews are effective forms of preparation that can help the interviewer feel more comfortable prior to interviewing patients. Conducting interviews with seriously ill participants with self-care in mind will allow the interviewer to do the job well.

CONCLUSION

We have used these interviewing methods in the field and have found them to enhance the quality of data as well as participant rapport. The techniques presented may be used with patients, family members, and clinicians, all of whom struggle with end-of-life issues. Family members may themselves be physically and emotionally fragile, and clinicians may feel vulnerable when asked about how they approach the end of life. End-of-life communication can be difficult, and this difficulty carries over all too easily into end-of-life research. With some attention to technique, however, the end-of-life interviewer can succeed in uncovering remarkable phenomena in a manner that is comfortable for both the participant and interviewer, and that can ultimately inform subsequent programs, policies, and clinical practice.

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Table 1

Twelve Techniques for Conducting Qualitative Interviews with Seriously Ill Individuals about End-of-Life Issues

Technique #1: Find a recruiter who knows the participant pool.
Technique #2: Take adequate time with obtaining informed consent.
Technique #3: Foster a sense of trust and safety from the outset of the interview.
Technique #4: Develop a sense of the participant.
Technique #5: Meet the participant where he or she is.
Technique #6: Start with safer ground and peel back the layers.
Technique #7: Go slowly.
Technique #8: Go where the participant goes.
Technique #9: Redirect the participant appropriately.
Technique #10: End in a way that allows the participant to reflect and regroup.
Technique #11: Wear only your interviewer hat.
Technique #12: Interviewer reflection.