

Table 46: Royak-Schaler 2006³⁹⁸

Study (ref id)	Royak-Schaler 2006 ³⁹⁸
Aim	To assess healthcare provider communication about end-of-life (EOL) and hospice care with people with terminal cancer and their families, from the perspective of the family members.
Population	FAMILY: 24 spouses and first degree relatives of deceased people with cancer who had been treated at the cancer centre from 2000-2002.
Setting	USA
Study design	Exploratory qualitative study using focus group discussion.
Methods and analysis	<p>A qualitative study design was used to examine communication and decisions about EOL and hospice care from the perspective of spouses and first-degree relatives of deceased people with cancer.</p> <p>A list of potential participants was generated from the medical records of 300 people with cancer who had died from October 2000-August 2002. In these records, 149 spouses or first degree relatives were identified. Of the 77 who were contacted successfully, 24 completed the study, resulting in a 31% response rate. The most common reasons people gave for declining to participate were that they were still in too much pain related to the death or that they lived too far away to attend the focus groups. Participants ages ranged from 26-77 years (mean 57.3); most were female (79%); Caucasian (71%) and spouses (75%) of a deceased person; all had graduated from high school; more than half were college graduates and most earned less than \$35,000 a year. Sixteen participants (67%) reported that their loved ones received hospice care delivered by a hospice team at EOL, 8 in their homes, give in an inpatient hospice and 3 in a hospital setting.</p> <p>Family members participated in 1 of 2 focus group discussions and completed a short self-administered questionnaire regarding their sociodemographic characteristics and the type of EOL care their deceased relative had received. Two 2-hour focus groups were conducted during March 2003 at the University of Maryland Medical Centre. Group leaders facilitated discussion, following a moderator guide that was designed to allow for the standardisation of questions and data collection methods for the 2 groups. In both groups, the same patient vignette was used to open group discussions.</p>

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	Qualitative data were audiotaped and analysed by comparing, contrasting and summarising content themes from the focus groups using NUD*IST 5 (N5) software.
Themes with findings	<p>Access to healthcare team and quality of provider communication:</p> <p>Some participants believed that the staff was too busy to adequately explain their loved one’s status to too busy to provide quality care. As a result, some participants questioned the competency of the healthcare team.</p> <p>‘I had to be the manager of her care, and you do because you don’t have an advocate in the hospital. Doctors are too busy and nurses are too busy to be an advocate for a particular person, so the caregiver is the advocate and you’ve got to watch every single thing.’</p> <p>‘You start feeling like you have to be a nurse of your own to get through the situation. We never saw the doctor, but I guess we saw the resident who had been working 36 hours straight ... that may be part of the hospital life, but sometimes it’s hard, it rubs you a little. You just feel like, God, am I getting the right care?’</p> <p>Accurate information that was communicated clearly to patients and family members was appreciated. According to 1 participant, ‘the staff are excellent ... they know, I could call them and they would direct me in the way that I should go, and I thought that was really nice.’</p> <p>Communication about disease progression and available care options:</p> <p>Focus group participants repeatedly commented about the need for more information from the healthcare team regarding the stage of disease and treatment decisions. When available, sufficient and accurate information helped them make informed decisions and feel comfortable with their loved one’s care, even when the final outcome was death. When information was freely available and compassionately shared, perceptions were more positive.</p> <p>‘Everyone that we had to deal with was kind and considerate, and they answered our questions and they helped us to understand what was going on, what his options were.’</p> <p>‘[My father] didn’t complain or ask questions, and it was important for me to get this information or to have the doctors explain everything to him very clearly because he was able to make a decision on his own and I didn’t want to have to make a decision for him. When he was informed, and the family members were informed, and he made the choice, we felt more comfortable as to whatever happens. We were thoroughly informed, and my father chose not to go with chemotherapy. He decided that he wanted to live his life but the way he wanted and be in control, so I thought that was very, very good.’</p> <p>Language, timeliness and sensitivity of communication:</p> <p>Many participants reported difficulty understanding the information that healthcare professionals provided. In addition, they indicated that such difficulty affected the ability of patients, when possible, or relatives (on behalf of the patients) to make EOL decisions. Unfortunately the language and medical terminology used by healthcare providers sometimes impeded understanding.</p> <p>‘I think the medical people assume that we know a lot about these disease and thing, but we don’t ... and thank God for the internet, because I went home and I became, not an expert, but knowledgeable of cancer and stage IV ... I had all the printouts and everything, but something like that, why do they assume that I know what stage IV cancer is?’</p>

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	<p>Participants reported that time was an important obstacle to effective communication.</p> <p>‘I had a complaint too, about, in fact, one of my very few complaints was getting information results of [computed axial tomography] scans to see whether the treatment was working or wasn’t working. I found it very difficult to get a timely output from the oncologists ... the difficulty was getting the information in a timely fashion.’</p> <p>Although some focus group participants preferred healthcare professionals to openly communicate information about the stage of disease and treatment decisions, the data indicated that others preferred just the opposite – especially when the information was shared in the presence of the patient. Some participants described experiences in which they felt that healthcare providers used language or shared information that was inappropriate because of its potential impact on the patient.</p> <p>‘After it was mentioned the he may have 2 weeks to live, that’s when my husband started saying, “Leave me alone. Let me die in peace.” That’s when he gave up, and I think those situations should be discussed away from the patient so they can have some hope.’</p> <p>Sources of bias in patient- and family –provider communication:</p> <p>Participants were asked whether they believed that healthcare providers demonstrated any biases or beliefs that affected patient EOL communication. No one reported racial or gender discrimination, although several mentioned possible age biases by healthcare professionals. One man explained that because his dying brother was young and had a close relationship with his healthcare providers, they had difficulty telling the dying person that he was close to death. Another participant believed that information to promote informed decision-making about hospice care was given only to older people.</p>
Limitations	Serious limitations. Sample size was small.
Applicability of evidence	Indirect population- In addition, the educational back group of the participants (42% high school graduates, 58% college or beyond) was higher than that of the general population. All participants were family members of deceased people with cancer who were treated at 1 site both of which limit generalizability. Setting outside of UK.