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More Than Words: Patients' Views on Apology and Disclosure When Things Go Wrong in Cancer Care

Kathleen M. Mazor[1], **Sarah M. Greene**[2], **Douglas Roblin**[3], **Celeste A. Lemay**[1], **Cassandra L. Firneno**[1], **Josephine Calvi**[3], **Carolyn D. Prouty**[4], **Kathryn Horner**[2], and **Thomas H. Gallagher**[4]

[1]Meyers Primary Care Institute, University of Massachusetts Medical School, Fallon Clinic, Fallon Community Health Plan, Department of Medicine, Worcester, MA, USA

[2]Group Health Cooperative, Group Health Research, Seattle, WA, USA

[3]Kaiser Permanente Georgia, Center for Health Research, Atlanta, GA, USA

[4]University of Washington, Department of Medicine, Seattle, WA, USA

Abstract

Objective—Guidelines on apology and disclosure after adverse events and errors have been in place for over five years. This study examines whether patients consider recommended responses to be appropriate and desirable, and whether clinicians' actions after adverse events are consistent with recommendations.

Methods—Patients who believed that something had gone wrong during their cancer care were identified. During in-depth interviews, patients described the event, clinicians' responses, and their reactions.

Results—78 patients were interviewed. Patients' valued apology and expressions of remorse, empathy and caring, explanation, acknowledgement of responsibility, and efforts to prevent recurrences, but these key elements were often missing. For many patients, actions and evidence of clinician learning were most important.

Conclusion—Patients' reports of apology and disclosure when they believe something has gone wrong in their care suggest that clinicians' responses continue to fall short of expectations.

Practice Implications—Clinicians preparing to talk with patients after an adverse event or medical error should be aware that patients expect their actions to be congruent with their words of apology and caring. Healthcare systems need to support clinicians throughout the disclosure process, and facilitate both system and individual learning to prevent recurrences.

Corresponding Author at (also responsible for reprint requests): Kathleen M. Mazor, EdD Meyers Primary Care Institute 630 Plantation Street Worcester, MA 01605 Phone: (508) 791-7392 Fax: (508) 595-2200 Kathy.mazor@meyersprimary.org.

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*I confirm all patients/person(s) have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

1. Introduction

The last decade has witnessed a concerted effort by healthcare organizations and clinicians to communicate more effectively with patients following adverse events and errors.[1] Hospital accreditation standards and some state laws require that patients be informed about all outcomes of care, including “unanticipated outcomes”.[2, 3] Institutions, healthcare systems, states and countries have developed and implemented policies on disclosure of adverse events and medical errors, and emphasize the importance of both sharing information about the event and offering an empathic apology. One influential disclosure policy is the Harvard Consensus statement, “When Things Go Wrong” [4]; similar recommendations by other national organizations exist.[5, 6] Policies vary, but most call for an explanation of what occurred, a statement of responsibility, an apology with an expression of regret, and a statement that efforts will be made to prevent recurrences. Some organizations are also developing mechanisms for making rapid and fair offers of compensation following harmful errors.[7]

Policies, consensus statements and opinion pieces reference research findings, but may not add to an evidence base. Further, such documents usually reflect the perspectives of clinicians and healthcare leaders, rather than of patients and family members. There has been relatively little empirical research into patients' perspectives on disclosure. Studies of lay people asked to imagine themselves in hypothetical situations involving medical errors have found that lay people respond more favorably when clinicians are forthcoming about what happened, accept responsibility, apologize, and refer to efforts to prevent recurrences.[8–11] Further research into patients' actual experiences with errors are needed to understand patients' preferences for disclosure and apology, as well as their actual experiences.

Despite the widespread dissemination of disclosure guidelines, clinician surveys suggest a persistent gap between recommendations for apology and disclosure and current practice,[12, 13] and physicians' responses to hypothetical errors reveal numerous shortcomings.[9, 14] One study of patients who had participated in disclosure conversations under a new policy revealed mixed results, and suggested apologies and changes in practice were not communicated.[15] Our study of parents who believed their child had experienced a medical error also identified deficits in clinicians' responses; most parents reported no one had explained what went wrong, and felt that no one involved understood the full impact of the event.[16] Failed disclosures can disrupt patient-clinician relationships, and may increase the chances of malpractice litigation.[17] These studies indicate a continuing need to examine patients' perspectives on the specific components of an effective response.

Cancer care, with its attendant communication tensions and challenges, is inherently stressful for patients. It is complex, usually involving multiple clinicians, toxic therapies, uncertain outcomes, and severely ill patients, and the potential for adverse events and medical errors is great. Patients with cancer are physically and emotionally vulnerable, and rely on their clinicians for information and emotional support as well as for medical care.[18] Communication breakdowns during cancer care may damage the patient-clinician relationship, negatively impact care, and result in worse outcomes.[19, 20] The consequences of adverse events and errors can be devastating for patients with cancer, making effective communication after such events crucial.

We explored patients' perspectives on problematic events and on clinicians' responses to these events. We sought to identify the key elements of apology and disclosure, to compare how these key elements matched current recommendations, and to determine the extent to which clinicians' responses were consistent with recommended practices.

2. Methods

2.1 Study Setting and Sample Selection

This study was conducted in the context of Cancer Communication Research Center, which is affiliated with the HMO Cancer Research Network (CRN). These National Cancer Institute-funded projects involve a consortium of research organizations affiliated with integrated healthcare delivery systems, and work to improve cancer care through a program of population-based research. Three CRN sites located in Washington, Massachusetts and Georgia participated.

Patients who had received treatment for breast cancer (women only) or gastrointestinal cancer (men and women) 6 to 18 months prior to the study period, but who were not actively undergoing treatment at the time of the study, were identified through electronic health system records. We anticipated that these patients would be over the initial shock and distress of the diagnosis, but their experiences would be recent and salient.

The study protocol was approved by the Institutional Review Boards of the participating healthcare systems.

2.2 Recruitment and Eligibility

Potential participants were invited by letter; follow up telephone calls were attempted 1–2 weeks later. Patients who expressed interest were screened to determine if they believed that: 1) something “went wrong” during cancer care, 2) the event could have been prevented, and 3) the event caused, or could have caused, harm. Eligibility required affirmative answers to all three questions. Harm was not limited to physical harm, but included psychological harm and other negative consequences. Additional eligibility criteria were willingness and ability to participate in a subsequent 1 hour telephone interview in English.

2.3 Interview Content

The interview guide was developed using an iterative process. Major interview domains were identified based on the existing literature. The draft guide was reviewed by the multi-disciplinary investigative team and revised. It was then pre-tested with patients not in the study sample, and revised again. Final interview questions focused on the event which the patient identified as something which had gone wrong, the impact of the event on the patient and family, communication with clinicians around the event, the patient's reactions to the event and the clinicians' response, and the patient's recommendations for improving care and communication during cancer treatment. The interview domains considered and illustrative interview questions used in the analyses are presented in Table 1. This paper focuses on patients' descriptions of their interactions with clinicians after the event, and on the extent to which patients felt these interactions were responsive and sufficient.

2.4 Data Collection Protocol

The **semi-structured** interviews were conducted via telephone by a trained, experienced interviewer, who first confirmed consent. The interviewer used a detailed interview guide, but varied question wording and sequence depending on the interviewee's response. She used probes to clarify and explore the meaning of interviewees' responses.

Limited demographic data, including age and level of education, were collected. Interviews lasted approximately one hour, were digitally recorded and professionally transcribed. Participants received $25.

2.5 Data Analysis

Transcripts were coded using directed content analysis.[21] Initial coding categories were created based on the interview questions; categories were refined through an iterative process of transcript review, coding, and discussion, until the team concurred that final coding categories captured the major substantive content of all reviewed transcripts. Four coders independently coded transcripts, discussed discrepancies, and suggested modifications. This process was repeated until agreement was >80%. The remaining transcripts were assigned to a coder, with **over ten percent of all transcripts** double-coded to provide a continuing check on coding consistency. At least one other team member reviewed each coded transcript, and confirmed coding accuracy. Codes were initially entered into word processing files, subsequently text and codes were entered into SPSS to facilitate manipulation and summarization. For the present analysis codes referring to actual and preferred clinician responses to the event were identified, and relevant transcript extracts were re-reviewed to identify additional sub-domains.

2.6 Role of the Funding Source

The NCI funded the study [P20CA137219], but had no role in the design and conduct of the study, the collection, management, analysis or interpretation of data, the preparation, review or approval of the manuscript, or the decision to submit the manuscript for publication.

3. Results

3.1 Sample Characteristics

The results of the patient selection and recruitment process are summarized in Figure 1. Of 708 patients initially identified through automated healthcare system records, 78 completed an in-depth interview. Participant characteristics are summarized in Table 2.

3.2 Events Identified by Patients

Patients described three types of perceived wrongs: 1) breakdowns in medical care; 2) breakdowns in communication, *without* a co-occurring breakdown in another aspect of medical care; 3) breakdowns in both medical care and communication.

Twenty-two patients described an event where the perceived “wrong” was a breakdown in medical care. The most common events in this category were perceived delays in diagnosis and/or treatment of cancer. Other events involved surgical problems, such as a need for additional surgery, infections delaying recovery, and delayed clinician response to surgical complications or chemotherapy side effects.

Thirty-seven patients described events in which the perceived wrong was a breakdown in communication, *without* a co-occurring breakdown in another aspect of medical care. Examples of these events include insufficient information provided to the patient (e.g., patient not told about treatment options), inaccurate information given to the patient (e.g., patient told that her cancer was life limiting, when test results revealed it was early stage and treatable), and the clinician not listening to the patient (e.g., dismissing patient reports of symptoms). Also categorized here were patients' reports that the clinician or another person in the healthcare system, displayed a cold or uncaring manner, sometimes tied to the delivery of the diagnosis, treatment decision-making, or interactions during chemotherapy sessions. Breakdowns in information exchange and manner were not mutually exclusive; some patients described both.

Nineteen patients reported events involving breakdowns in *both* medical care and communication. Most frequent were perceived delays in cancer diagnosis and treatment, with poor information exchange leading to or increasing the delay. Other examples included infections and post-surgery complications which the patient believed were exacerbated by the clinician's unresponsiveness to the patient's reports; and insufficient information provided to the patient leading to poor decision-making (on the part of the patient) and/or unnecessary pain.

3.4 Patients' Perspectives on Clinicians' Responses

3.4.1 Provide information on what happened—Acknowledgement of the event and information about what had occurred were important to patients in two ways. First, some patients simply wanted to know and understand what went wrong. As one patient said, “I've been really impressed with the time he took to explain in a straightforward manner.” But an explanation of what happened was important in a second way as well; many patients felt it was critical that that *those involved* in the event know and understand what went wrong. Comments relating to the clinician's understanding were much more common than comments related to the patient's personal desire to understand. Several patients wanted an explicit acknowledgement of the specific offense or lapse. Suggestions for what clinicians should have said included “I'm sorry, I made a mistake” “I made a mistake, I should have gloved up” and “I'm so sorry that I said this to you. This was wrong. I really should have waited until we had more information.” One patient hinted at the link between acknowledgment of the event and competence when she said that an acknowledgement would have “made me feel better about the care and the team, knowing that they really know what they're doing and that they understand their patients.”

3.4.2 Apology and Expressions of Regret—Patients valued apologies, including expressions of regret, concern, caring, and empathy. Many patients made positive references to such statements; many others who had not received apologies or empathic responses expressed anger or unhappiness about the omission. Some patients received an apology from someone other than the person seen as responsible; such apologies were also viewed positively. As one patient said, “The fact that other people apologized for her actions made me felt that they felt really bad that that had happened to me.” Implicit in this quote is the importance of recognizing the impact of the event on the patient. This was echoed by other patients, for instance by one who said “I think [she] did the right thing… she acknowledged that I'd been through a pretty terrible experience.”

For some patients, statements of apology and caring were **more** important than explanations of what happened. As one patient said, “… trying to explain it to me, I don't know if that would have helped any. … I think what I really wanted was someone to care, to say, `Oh I am so sorry…'”. One of the few patients to receive an apology explained its significance and effect on her: “And she [the PCP] was sad, too, but she was in congruence with my emotions. She wasn't trying to pretend that nothing had happened…That made a huge difference. She was just very sincere and authentic.”

Several patients' comments referred to the limits of apology. For example, one patient who had received an apology noted that it had not been sufficient to “bridge the trust gap” and another felt that an apology would be appreciated, but it “…wouldn't make me go back to her.” Apology alone was not considered a sufficient response to incompetence. As one patient said: “I don't think someone else apologizing for their behavior would have necessarily made me feel any better, because I truly don't think this particular office … I just don't think they know any better.”

3.4.3 Responsibility—Patients confirmed the potential value of acknowledging responsibility for an event or error. As one patient said, “… taking responsibility, that's kind of what it's all about.” Assuming responsibility also served as an acknowledgement that the patient suffered harm as a result of the event, and therefore strengthened the apology. A patient who felt positively about her primary care clinician's response said “…it made me feel that I could trust my PCP because, I mean she took responsibility … had remorse about what happened. She wasn't defensive.” Another patient linked responsibility and apology; she did not want an apology “…because he didn't really admit to it anyway. You know, you can apologize, but if you're not saying that you really did something …” Finally, some patients saw responsibility as prerequisite to learning. One patient said: “…it goes a long way for me if a person can acknowledge, `I made a mistake.' And it goes even further for me if they say what they're going to do differently. And I didn't get that. I didn't get that from the surgeon, and I really don't know whether she thinks she made a mistake even.”

3.4.4 Preventing recurrences—Patients spontaneously and repeatedly noted the importance of preventing recurrences, referring to both individual- and system- level changes. This theme was expressed succinctly by a patient who said, “The important thing is that it doesn't happen again.”

The other elements of disclosure - acknowledgement of the error, explanation of what happened, and apology, all related to the importance of preventing recurrences. One patient said “…the point that should be made is that she knew she made a mistake and will try harder not to do that again to anybody else.” Another patient linked understanding what had gone wrong to preventing recurrences saying, “Well I think he should have [gone] further in trying to figure out what did happen, because he does that surgery all the time. He could endanger some other woman's life.” Patients referred to importance of the clinician learning from the error. One patient noted that she would “feel real good [sic]” if her clinician said `I've learned something from this'. Another patient wanted her physician to say “I'll make my best effort to become more educated about this.”

Patients also expected that clinicians had learned from past errors. One patient articulated the desire for an explanation with the desire to know that she was not the victim of a recurring problem when she said, “I think he should have at least confirmed, `Whoa, that is an oversight … I'm sorry that it happened, it has never happened to me.' Some further explanation. Give me the assurance that this is not a common occurrence.”

3.4.5 The importance of action—Patients stressed the importance of action, and the need for actions to be congruent with words. As one patient said, “If you're going to apologize and you're not going to fix anything, that's just insulting my intelligence.” Another patient said “There's got to be accountability. I don't want to hear, `I'm sorry.' `I'm sorry' is nothing.[sic] I want to know what steps have you taken to correct the problem? Don't tell me you were sorry that the problem occurred. That just puts a band-aid on something. …. I want to see results.”

Action was also important for patients who expressed a desire for help in remedying their own situation. As one patient said “I would have liked him to say, `… let's go and find out what happened here and take care of it.' ” Another patient wanted to hear “What can we do to fix this? How can we make this right?” However, not all patients believed that remedies were available; some felt that the harm could not be undone.

3.4.6 Financial Reparations—Only two patients expressed a desire for financial reparations; both referred only to costs incurred. One patient suggested that an appropriate response to the wrong she had experienced would be to “…say, `Hey, I'm going to waive all the co-payments for anything that was related to cancer from the time this began. And I'm going to cover all of your financial expenses for travel'…” Another patient referred to an offer to cover costs as desirable in the context of apology, recommending that the clinician say “I'm so sorry that this happened… If there's any way we can compensate you for the money that you've spent …”

3.5 Patients Experiences of Disclosure Elements

Considering the four key elements of disclosure (apology, explanation of what went wrong, acknowledgement of responsibility and commitment to prevent recurrences), the vast majority of patients in this study felt that most elements were missing from their experience. Only fourteen patients reported that at least one of the four elements of disclosure were present after the event which they perceived to be a wrong.

4. Discussion and Conclusion

4.1. Discussion

The views of the patients in this study, all of whom believed they had experienced a preventable wrong in their care, suggest that while the elements of disclosure set forth in the Harvard consensus statement are important to patients, actions speak louder than words. Patients value expressions of regret and empathy, but without action, words of regret or remorse may seem meaningless, empty or even insulting. Patients expect and appreciate help in righting whatever went wrong in their care, and they expect that individuals, teams and systems will work to prevent recurrences for future patients. Whether it is due to a desire for justice,[22] for evidence that those involved take the event seriously,[23] or reassurance that their suffering had value, patients clearly prioritize efforts to prevent recurrences. An error may be forgivable, but not learning from the error is not. Concerted effort on the part of the healthcare system may be needed to fix problems in care, which is why disclosure is an institutional responsibility. Organizations may think that patients are looking for results of root cause analyses or similar reports, and in some cases they may be, but the needed “action plan” may be as simple as a statement that the clinician has learned from the mistake. Clinicians and organizations have more work to do both in preventing recurrences, and letting patients know that such efforts are underway.

These findings also suggest a continuing gap between patients' expectations for apology and disclosure, and their experiences of actual apologies and disclosure conversations. **The patients in this study** cited numerous instances of missing or ineffective responses from clinicians. **The apparent persistence of this gap** despite the attention to apology and disclosure in recent years is discouraging. If patients do not express their concerns, clinicians may be unaware of them. This might account in part for the fact that clinicians' responses were often missing in the present study. In practice, clinicians should be alert to the potential for unspoken concerns, and periodically check with patients' about their experiences. Systems-based approaches for collecting patients' reports of their care experiences – both good and bad – could also be helpful.

These patients saw acknowledging responsibility for a wrong as directly related to learning and preventing recurrences. Patients seem to think (reasonably) that if no one takes responsibility, things will not get fixed. Accepting responsibility is hard for clinicians, in part due to liability concerns. Clinicians worry that explicit acknowledgement of actions which contributed to an adverse event will make them vulnerable to malpractice suits. Risk managers and other organizational representatives sometimes share such concerns, and reinforce reticence about responsibility. Clinicians' perceptions of responsibility may differ from patients', as they may attribute problems to system errors, rather than personal errors. Such attributions could cause a clinician to refrain from personally accepting responsibility. Responsibility for things going wrong may be particularly difficult to assign in cancer care, where multiple clinicians are involved. To the clinical team, this may mean that no single clinician is responsible for a breakdown in care; however the patient still needs someone to relate to. None of the patients in this study referred to a group meeting about an event, though some described successful, satisfying meetings with a single clinician about an event that involved a team. Other patients had satisfying 1-on-1 interactions with clinicians who were not involved in the problematic event, but who were providing care at a later point in time. From the point of view of the patient, having someone willing to take responsibility and action was valuable, even if it was not the person they viewed as directly responsible. Team disclosure has been largely understudied, and many questions relating to team disclosure remain unanswered.

Sincerity is important in apology; an apology which is judged insincere may actually damage the physician-patient relationship. Conveying sincerity may be challenging. Our findings suggest that patients consider the clinician's actions and words together in evaluating sincerity. Patients looking for responsibility *and* corrective action may doubt the sincerity of expressions of regret actions are missing; such responses may even be perceived as indicative of incompetence or lack of caring.

The above is not to imply that patients do not value explanation and apology – they do. One component of apology which has received little recognition in the literature to date is recognition of how the event affected the patient. Patients want recognition not only of physical suffering and emotional distress, but also of the impact of the event on their day to day life, their work, and their family.

There is an additional important caveat to the above discussion –not every component response will be appropriate to every situation. At the same time, for many patients the absence of one element weakens the effect of the others. Patients vary in their expectations and desire for apology and disclosure, and matching the patient's needs provides an additional challenge to clinicians.

4.1.1. Limitations—We did not review medical records, or determine whether the events patients identified represented actual medical errors. As in any study which requires active participation, participants may differ in important ways from non-participants, potentially limiting generalizability. Similarly, while the experiences of these patients suggest a substantial gap between recommended and actual practice, we are unable to determine whether their experiences are typical. A further limitation is the fact that the vast majority of patients were women with breast cancer; men and patients with other cancers might have differing experiences and hold differing views. Finally, selective remembering and forgetting may have affected patients' reports.

4.2. Conclusion

Patients' reports of their experiences with apology and disclosure **when they believed that** something went wrong during their care suggest that disclosure often does not occur, and when it does occur, critical components may be absent. Patients want more than words of regret –they want those involved to recognize the full impact of the event, to take responsibility and to take action taken to prevent recurrences. Clinicians may find these expectations daunting, given the complexity of the healthcare system and concerns about liability.[9, 24] Clinicians and teams need training and support around apology and disclosure, and healthcare systems need to accept responsibility for disclosure and for systems improvements.

4.3. Practice Implications

Clinicians preparing to talk with patients after an adverse event or medical error should be aware that while patients value apology, explanation and responsibility, words may be perceived as empty or insincere if they are not accompanied by appropriate action. Acknowledging responsibility and committing to preventing recurrences may be challenging for some clinicians, but are important to patients.

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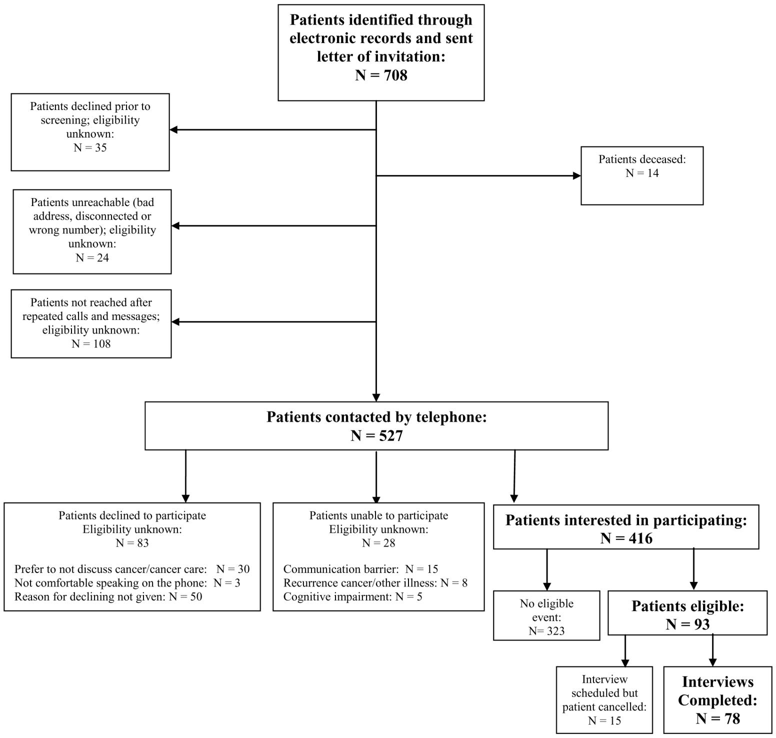

Fig. 1.

Summary of patient selection and recruitment process

Table 1

Major Interview Domains and Illustrative Questions

Interview Domain	**Question(s)**
Communication with Clinicians *After the Event*	Did you talk to [ ] about what happened?
	Did [ ] explain what happened?
	Did [ ] apologize?
	Did this change how you felt about what happened?
	Do you feel that [ ] took responsibility for what happened?
	Did anyone say anything about making sure what happened to you didn't happen again to someone else?
Perceptions of Clinicians' Response *After the Event*	Was there anything you wish that anyone had done differently?
	Can you think of anything that anyone did that was especially helpful?
	Can you think of anything that anyone at did that was very unhelpful?
Probes	Could you tell me more about that?
	What words did they use to talk about what happened?
	Did you feel the explanation was clear?
	After the conversation, did you feel you understood what had happened?
	What else would you have wanted [responsible person] to say?

Table 2

Patient Characteristics

Age (mean, range)	58 (36–79)
	N (%)
Gender	
Female	75 (96)
Male	3 (4)
Highest Education	
≤High School	13 (16.7)
Some College	21 (26.9)
4 Year Degree	18 (23.1)
> 4 Year Degree	26 (33.3)
Cancer Type	
Breast	70 (89.7)
Gastrointestinal	8 (10.3)
Race	
Caucasian	55 (70.5)
African American	18 (23.1)
Asian	2 (2.6)
Native American	1 (1.3)
Multi/Other	2 (2.6)
Hispanic	
Yes	1 (1.3)
No	77 (98.7)
First Language	
English	74 (94.9)
Other	4 (5.1)
Marital Status	
Married	47 (60.3)
Divorced/Separated	19 (24.4)
Widowed	6 (7.7)
Single	6 (7.7)
Working Status	
Full Time for pay	37 (47.4)