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Awareness of Dying Remains Relevant after Fifty Years

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Abstract

This year is the fiftieth anniversary of the publication of *Awareness of Dying*, one of four monographs that culminated from a six-year funded research program titled Hospital Personnel, Nursing Care and Dying Patients (Glaser, 1968). Written by Barney Glaser and Anselm Strauss, *Awareness of Dying* (1965) was the first published study utilizing a new, groundbreaking research method. Glaser and Strauss termed this new method grounded theory because it was based upon data that was grounded in the real-live experiences of people. In this paper, we will look back at the origin of the grounded theory method and re-examine Awareness of Dying in light of more recent research in the area.

Keywords: awareness of dying, dying process, end-of-life care, grounded theory.

Introduction

Following publication Awareness of Dying, Glaser and Strauss published a detailed description of the new method that they used to discover the theory. The grounded theory method was derived from a melding of the authors' backgrounds: Glaser's study of quantitative and qualitative math at Columbia University under Lazarfeld, his study of *explication de texte* at the University of Paris, his study of theory construction under Merton, and Strauss's study of symbolic interactionism under Blumer at the University of Chicago (Glaser, 1998; Glaser & Strauss, 1967). Their meticulous description of the method in a subsequent publication, The Discovery of Grounded Theory (1967), provided the structure for others who would subsequently use the method. It also garnered respect because it took advantage of reputable mathematic quantitative and qualitative ideas.

Some would say that theory that is grounded in the experiences of people is the most important and distinctive scientific activity for human beings because theories depict a meaningful pattern. Because of this real-world orientation, grounded theories offer clear understandings of predictable processes and patterns of behavior. Grounded theories help us to understand that when certain patterns emerge, particular people respond in predictable ways and their actions produce predictable results (Nathaniel, 2007). When we understand patterns that affect people, we can work towards altering them. Thus, theories have the potential to give us more insight and control in predictable situations.

Awareness of Dying 1965

Awareness of Dying is historically important because it was the first grounded theory ever published. For six years, Glaser and Strauss conducted intensive fieldwork involving a combination of observations and interviews at six hospitals. The purpose of their research was to contribute toward creating end-of-life care that was more rational and compassionate. The investigators were allowed to observe different aspects of dying within these six hospitals; death at these locations was "sometimes speedy, sometimes slow; sometimes expected, sometimes unexpected; sometimes anticipated by the patients, sometimes unanticipated" (Glaser, 1968). The researchers observed nurses and physicians at work. They sat at the nurses' stations, attended staff meetings, and talked with patients. They also asked questions and interviewed staff. The theory that emerged from this intense investigation presented an eye-opening view of how patient care was affected by the awareness level of the dying process by nurses, physicians, and patients.

Today, most people choose to die in hospitals, hospices, and nursing homes. The situation was much the same in the 1960s. When people die in institutions, nurses and physicians, who are virtual strangers, are responsible for care during the last days of life. During the course of their observations, Glaser and Strauss found that Americans hesitated to talk openly about dying and were prone to avoid telling a person that he or she was dying. We know now that grounded theories uncover previously unknown processes. So, it is not surprising that Glaser and Strauss were able to identify previously unknown levels of awareness of impending death and the affects these levels have on patients, relatives, nurses, and physicians. What emerged during their investigation was four distinctly different awareness contexts: closed awareness, suspected awareness, mutual pretense awareness, and open awareness. The following section encapsulates the major concepts of the theory of Awareness of Dying as described by Glaser and Strauss (1965).

During their investigation, Glaser and Strauss found that U.S. physicians were reluctant to disclose impending death to their patients, and nurses were not allowed to disclose information without the consent of physicians. Nursing and medical education were focused on the technical aspects of dealing with patients, with little exposure to psychological aspects of care. This limitation led to what Glaser and Strauss termed closed awareness of dying.

Closed awareness denotes a context in which patients are not aware of their own impending death. Staff members understand that the patient is dying, but cooperate with each other to maintain the fiction that the dying patient might recover. They carefully avoid arousing the patient's suspicions. Tactics nurses and physicians use to maintain closed awareness include giving patients an incorrect or partial diagnosis, manipulating the conversation so that patients will make inaccurately optimistic interpretations of their situation, and spending little time with patients to minimise possibly revealing cues. They avoid doing anything that might arouse patients' suspicion. Having the false belief that they will recover, patients are not allowed the benefit of closing their lives with proper rituals. Friends and relatives are also affected because they cannot openly express their grief in the presence of their loved one. Even so, there comes a time when patients become suspicious that they may be dying.

In suspicion awareness patients do not know for certain that they are dying but they suspect, by varying degrees, that the physicians and nurses believe them to be dying. When they become suspicious, patients engage in strategies that might confirm their suspicious, even though they have they have few resources with which to find out the truth. Strategies might include announcing their impending death for the purpose of checking the reaction of staff members, asking about symptoms while listening intensely for clues that they are dying, or attaching significance to every word and gesture of staff members. Even though they are seeking to confirm their suspicion, patients likely do not have sufficient medical knowledge to interpret the cues. As time passes, staff members gauge patients' level of awareness. Once physicians or nurses perceive that patients suspect terminal illness, they use strategies similar to those employed in maintaining closed awareness to counter patients' suspicions. At this level of awareness, Glaser and Strauss found that staff members act as if patients are merely ill, but not dying, by conveying impatience with patients' suspicions and acting in a dispassionate, cheerful, or abrupt manner. Nurses and physicians may send a clear message that they are too busy to talk or tell patients to direct their questions to someone else. Essentially, nurses and physicians deny patients' claims by refusing invitations to talk. The state of suspicious awareness places patients, relatives, and staff under considerable strain and creates an atmosphere of tension. This type of context tends to evolve into other types such as mutual pretence.

Mutual pretence occurs when everyone involved knows the patient is dying, but all pretend otherwise. There may be some comfort in mutual pretence and all people involved must be careful to maintain this fragile illusion. Strategies employed to maintain the illusion include conversations that focus on safe topics and avoid dangerous ones. If something threatens the fiction, everyone pretend that it did not happen. One-by-one, pretence is added to pretence in order to conceal unintentional slips. Mutual pretence may ensure privacy and dignity for patients and minimize embarrassment for relatives. Staff members might feel relief, but mutual pretence has the potential to cause considerable stress for both relatives and staff. However, the atmosphere created during mutual pretence is generally one of serenity. As the situation progresses, this pretence is challenged by obvious physical deterioration or when patients feel they cannot face death alone. At this point patients make the transition to open awareness.

In the open awareness context, staff and patients acknowledge that the patient's condition is terminal. Open awareness is often a stable context. Patients understand that they are dying, but often remain in closed awareness about other aspects of death such as mode and time. Staff reveal these details only if they believe that they will not to be upsetting or unpleasant for patients. Even within the larger context of open awareness, holding back unsettling details creates a strategy of mutual pretence around particularly difficult issues.

Staff have certain expectations of patients. As patients become more aware of and take more responsibility for the dying trajectory, nurses and physicians expect them to behave with dignity and refrain from displaying their emotions. For example, patients are expected to continue the fight to stay alive unless suffering is intense or death is quickly forthcoming. Glaser and Strauss found that nurses and physicians appreciate patients who

die with dignity and grace. When patients are not perceived to be dying properly, staff might admonish, coax, or appeal to higher authority (a priest for example) to help control them. Within the context of open awareness, patients and staff negotiate to relax the usual hospital routine. Glaser and Strauss found that an attempt to relax hospital rules is more likely to be successful if staff consider patients to be dying in an "acceptable" way.

Many staff members, especially nurses, prefer open awareness since they get satisfaction from being able to comfort patients. Open awareness gives patients the opportunity to close their lives usefully, according to their personal thoughts about proper dying, and allows them to talk openly with relatives. Open awareness, however, has some disadvantages for patients. They may not be able to bring closure to their lives and may die with more psychological anguish and less dignity than those who die in closed awareness.

After Glaser and Strauss published *Awareness of Dying*, they wrote their ground-breaking textbook, The Discovery of Grounded Theory (1967), describing the new research method. Certain inferences can be made from a close examination of the tenets of the method as described in Discovery. Assumptions inherent in the classic method, are as follows: 1) There are happenings that can be objectively observed. 2) These happenings occur in predictable patterns that can be conceptualized. 3) Grounded theory seeks to understand processes from participants' perspectives—from their words and behavior. 4) Grounded theories are dynamic in that they consist of a set of interrelated tentative hypotheses that are modified as new facts emerge. Thus, a grounded theory that is built upon these underlying assumptions should endure over time since subsequent research serves to enrich rather than refute classic theories.

Awareness of Dying Today

Compared to 1965 when *Awareness of Dying* was first published, recent trends show a slight decline in the percent of people who die in institutional settings. Nearly 65% of people in the U.S. spend their last hours in hospitals and nursing homes surrounded by physicians, nurses, and other hospital staff (Centers for Disease Control, 2010). Since the publication of *Awareness of Dying*, much research has focused on end-of-life processes. In everyday practice today, nurses and physicians continue to control information and thus control the awareness context, either by delaying, modifying or tempering full disclosure, despite apparent commitment to open awareness (Field & Copp, 1999). However, awareness of dying remains desirable since it enables life planning to proceed and offers some control over the manner and timing of death (Seale, Addington-Hall, & McCarthy, 1997). It also enables individuals to exercise some control over their last months and days of life (Field et al., 1999).

There has been an increase in those dying in open awareness among people with cancer (83.9%), yet despite the influence of Glaser and Strauss's theory, this increase has not been reflected in other conditions such as end-stage cardiovascular (51.6%) and respiratory (71.4%) disease (Seale et al., 1997). Seale, et al. (1997) concluded that while open awareness is the most prevalent context, medico-biological factors, such as cause of

death, and socio-cultural factors, such as social class, contribute to variation in awareness contexts. Patients dying of cancer are more likely to receive a terminal prognosis in an explicit way compared to those with end-stage cardiorespiratory disease. This practice leaves patients to surmise that they are dying on the basis of their own knowledge (Exley, Field, Jones, & Stokes, 2005). However this finding is not universal. In a study of patient awareness of imminent death, nurses and caregivers said that 51% to 62% of patients had been aware of the imminence of death in the last days of life, despite 71% of patients dying from cancer (Lokker, van Zuylen, Veerbeek, van der Rijt, & van der Heide, 2012). This statistic still leaves a significant number of patients dying in closed awareness. Since the majority of patients who were unaware died in hospital, communication around dying and death still needs to be significantly improved.

Patients and physicians still engage in what is labelled "pretence awareness," in which both know the prognosis, but tell each other "recovery stories" (The, Hak, Koeter, & van Der Wal, 2000). Corresponding with Glaser and Strauss's concept of mutual awareness, pretence awareness leads to false optimism. Applying awareness theory, this is likely to lead to maintaining closed awareness. These recent findings demonstrate that there is still much room for improvement, particularly in relation to people dying with a diagnosis other than cancer. Patients need information to make treatment choices and take leave of loved ones (Francke & Willems, 2005). Research suggests that this can only be achieved in the context of openness.

Consistent with Glaser and Strauss's 1965 theory, poor communication between the terminally ill, their relatives, and hospital staff continues to be problematic (Yabroff, Mandelblatt, & Ingham, 2004). Many physicians feel unprepared to provide information about poor prognosis (Lamont & Christakis, 2001). There are also gaps in the training of other members of end-of-life health care teams (Rabow, Hardie, Fair, & McPhee, 2000). Against today's background of increased capacity for technological interventions, clear decisions about the right time to die may be more difficult than in the past, making it even more important for patients and their relatives to be involved in decisions about end-of-life care (DelVecchio et al., 2004).

Awareness of Dying has the potential to provide a very effective basis for dealing with these continuing problems since it can be used to guide communication between everyone involved in terminal care. For example, Glaser and Strauss discussed explicitly how to change awareness context and offered guidance on how to deal with potential problems as a consequence of changed awareness. Effective communication is powerful and a necessary condition for facilitating open awareness. It confirms humanity, instils a sense of security, and is essential to meaningful care (Ryan, 2005). Its importance was confirmed in a recent systematic review. The review noted that patients and their families consistently identify effective communication, together with shared decision making and expert care at the end-of-life, as the most important areas that need to be addressed (Virdun, Luckett, Davidson, & Philips, 2015). Despite the fact that these domains of care have been consistent for over two decades, they are often poorly addressed within the hospital setting. Communication especially continues to be inadequately addressed (Burg, Lawson, Johnson, Asada, McIntyre, Grunfeld, & Flowerdew, 2014). Health carers tend to

engage in mechanistic communication, which impedes discussion and fails to take into account relatives' understanding or prior experiences and is given a low priority (Caswell, Pollock, Harwood, & Porock, 2015). Uncertainty as to when death will occur further complicates communication. Glaser and Strauss (1965) identified and outlined a typology of death expectation as follows:

- Certain death at a known time.
- Certain death at an unknown time.
- Uncertain death but a known time when the question will be resolved.
- Uncertain death and unknown time when the question will be resolved.

The level of certainty has profound implications as to how the patients and their loved ones will be treated. It may, in part, explain difficulties around communication at this time, particularly when death and its timing is uncertain. This knowledge is particularly applicable to patients with a chronic illness, since it is very difficult to predict when they will enter the terminal stages of their disease. Some critically ill patients and those requiring intensive care are also in this category (Andrews, 2015).

Studies in the 50 years since *Awareness of Dying* was published have shown that awareness context has continued to shape discussions in relation to disclosure (Field & Copp, 1999) and has been instrumental in focusing care on the individual who is dying, rather than being primarily concerned with the protection of others through non-disclosure (Field, 1996). However, there is still much to be gained by applying Glaser and Strauss's awareness contexts to current health care practices, remembering that patients who are aware of the imminence of death are more often at peace with dying (Lokker et al., 2012).

Conclusion

Glaser and Strauss's grounded theory, awareness of dying, is as fresh and relevant as it was 50 years ago. This seminal theory offers a true-to-life conceptual picture that can be modified as newer research emerges. Our research has shown that the theory has endured for a half century and that contemporary studies complement, rather than refute it. Emerging research findings can modify the theory through enhancement and contemporaneous illustration. On a practical note, the theory will continue to serve as a guide to nurses and physicians. It will help them to think about predictable processes and to alter their actions in order to improve care of dying patients. At a basic level, the theory sensitizes health care professionals to universal problems that surround end-of-life care and provides them with a means of making things better. By applying elements of the theory, physicians and nurses are better able to deal with patients and families during the sudden transition from one type of awareness to another. The theory reveals how the context of patients,' physicians,' and nurses' awareness can determine how patients experience their last days. It teaches us that staff who are honest and sensitive to dying patients and communicate well may be able to better assist the dying to conclude their lives with proper

rituals. Thus, 50 years after it was first published, *Awareness of Dying* continues to reflect an important process within the health care system and to offer relevant implications for improving the quality of end-of-life care.

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