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ABSTRACT

Research with older persons suffering from physical illness presents numerous challenges to gerontologists. Issues of conceptualization pertaining to the definition of illness, its location in the research paradigm, and the context in which illness occurs must be addressed prior to dealing with methodological problems. Access to physically ill elderly persons is often controlled by health care providers who serve as gatekeepers and/or referral sources in a broad range of studies. The suspicion and reluctance of gatekeepers may be overcome by establishing contacts prior to soliciting participation and by considering the needs and perspectives of the institution. Informed consent is often difficult to obtain from older adults due to deep-seated fears, restrictions imposed by families, and ethical considerations. Foremost among sampling issues is the difficulty of obtaining a randomized sample due to the potential threats of survivorship, health status, health utilization, and special population biases. Research process issues are hampered by the paucity of appropriate instruments and the effects of the patient's illness on both the process and the content of interviews. Data interpretation must take into account the generalizability of findings given the sampling difficulties with this population. To address these methodological research problems, a dynamic model, in which physical and mental health, the interview situation, contextual factors, and patient responses serve as input variables, is proposed. (BL)

STUDYING PHYSICALLY ILL ELDERLY

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I Significance of Illness-Related Research

Research with older persons suffering from physical illness presents numerous challenges to gerontologists. Not only must we be mindful of special considerations in studies of the elderly in general, but superimposed are additional problems which are a function of physical health status of respondents.

High rates of chronic illness among elderly persons have been well documented. According to the National Center on Health Statistics (1981), over 80% of persons over age 65 suffer from at least one chronic illness. Awareness of respondents' health status is necessary in all aging research, whether among the frail elderly, the institutionalized aged, the elderly afflicted with particular illnesses or healthy aged persons since studies of "well" elderly, living in the community are likely to include persons with health problems. Thus, researchers must be sensitive to the many ways in which respondents' illness may impinge on research procedures and/or confound responses which are obtained. Respondents' health problems may affect all aspects of the research process, including design, instrumentation and data collection.

While this paper will offer suggestions for overcoming some special methodological problems in illness related gerontological studies, our primary intention is to sensitize researchers by pointing out major research issues. Many of these are depicted in a model to be presented. We hope that our discussion may generate suggestions for solutions which we had not considered and that we may identify areas of concern to other researchers working in diverse areas.

II Conceptual Issues in Illness Related Research

Investigators must face conceptual problems associated with illness research even before encountering methodological pitfalls. There are issues of conceptualization pertaining to the very definition of illness, its location in the research paradigm, and the context in which illness occurs.

At the outset, defining illness represents one of the most difficult challenges. Self and other definitions of illness may vary considerably, as has been shown by studies examining objective and subjective health reports (Filenbaum, 1979; Graney and Zimmerman, 1982; LaRue, et al., 1979; Mossey and Shapiro, 1982). Since patients and health care professionals typically use different criteria (Kahana and Coe, 1969), and there is no agreement as to which report is more valid, researchers are still grappling with the issue.

Another definitional consideration is raised by the heterogeneity of illness. In defining illness, we must differentiate between short term acute problems, long term chronic disease, and terminal conditions. While all of these are located on Twaddle's (1974) health-illness continuum, they differ both in kind and consequence.

A second conceptual issue involves the locus of illness in the research paradigm. Is it to be an independent variable or a dependent variable? Illness is one of the two best predictors of psychosocial well-being among the aged (Lee, 1978; Larson, 1978; George and Bearon, 1980). Yet illness is also one of the most frequently used outcome variables. In the literature on stressful life events, researchers have recently recognized the inappropriateness of illness being considered both as a predictor and as an outcome variable (Kahana and Kahana, 1983). It is important to guard against confounding by clearly denoting the location of illness variables in the research paradigm.

The context in which a situation occurs is also important to consider (Veroff, 1983). If researchers wish to conceptualize illness in a more comprehensive manner several contextual items should be addressed: the cultural context, the environmental context, the interpersonal context, and the therapeutic context. The cultural context includes influences such as sex, SES, and ethnicity. Patients are not homogeneous groups (Watson and Kendall, 1983), and there are considerable differences in sick role behavior, illness perception and even pain response according to socio-demographic characteristics (Zborowski, 1952; Zola, 1966; Twaddle, 1981; Larson, 1978; George and Bearon, 1980).

The environmental context can include both temporal and spatial factors. When and where the interview takes place can impact on answers given by respondents. If, for example, the day chosen to contact an asthma patient is very humid, breathing difficulties are likely which can influence response to items such as health perceptions. Spatial factors can also complicate research. Interviews conducted in a cold room may yield brief answers so that patients can terminate the session.

The interpersonal context relates to concerns such as the presence or absence of others during the interview. Patients in long term care facilities may fear being overheard by nurses or supervisory staff. In contrast, interviews conducted in respondents' homes could produce more candid responses as to health care providers and institutions.

It is also relevant to address the therapeutic context. Persons receiving certain types of treatment can exhibit particular behaviors. To illustrate, some medications produce side effects such as drowsiness or memory lapses, while procedures such as dialysis or chemotherapy may result in pain and discomfort to the patient.

Attention to definitional and conceptual issues can help researchers design studies of the ailing aged which are both methodologically sound and can provide meaningful answers to the research questions under study.

Design and Sampling Issues

A. Access and Gatekeeping

Academic researchers often encounter problems in gaining access to physically ill elderly. Health care providers typically serve as gatekeepers and/or referral sources in a broad range of studies including those of ill elderly in the community, those of patients in acute care hospitals and those focusing on elderly in chronic care institutions. For studies of community elderly, physicians, outpatient clinics, or foundations typically furnish patient pools. In chronic care facilities administrators usually serve as gatekeepers. In acute care general hospitals, gaining access is further complicated by the complexity of the organization. Facing the need to gain permission from hospital review boards and similar structures, the researcher must deal with bureaucratic procedures involving autonomous or semi-autonomous authority structures (Coe, 1978; Freidson and Rhea, 1965; Smith, 1955; Wilson, 1970).

Reluctance to participate in the research may be due to diverse concerns of gatekeepers who may be fearful to permit outsiders a closeup view of their operation. Concern with potential negative publicity is especially acute for long term care facilities in view of the poor image of nursing homes by the media and public. There is often little understanding or information as to what the referral source is to gain from an investment of staff time and permission of access to its clients. There may also be genuine motivation to protect the privacy of patients. In this view, research may be an imposition on patients' time and energy.

In order to facilitate the research there are some techniques which help to overcome suspicion and reluctance of gatekeepers. It is useful to establish contacts prior to soliciting participation for a specific project or to have someone known to the gatekeepers arrange an introduction.

Seriously considering the perspectives of the institution can be useful in that it enables researchers to offer something useful to gatekeepers. Perhaps tabulated data may be made available, or questions of particular interest to the referral source could be included in the research proposed. Providing administrators with previous written reports by the investigator may also be helpful and impressive.

B. Issues of Consent

The need for written consent for protection of human subjects makes research among the ailing aged more difficult. Some older persons who are otherwise pleased to cooperate feel that signing the informed consent form poses a special threat to them. We have often been told by potential respondents: "I would love to talk to you but my children told me not to sign anything." Others are concerned about release of medical records which may be necessary to gain objective reports of health status. Some respondents may be fearful that if they appear "too healthy" they may be denied health services while others may fear stigma of a particular health problem being revealed to "outsiders." These are deepseated and often unarticulated fears and are not always amenable to reassurances of anonymity by investigators.

Other concerns pose ethical dilemmas for researchers. As it is well known, truly voluntary participation is much more difficult for persons in institutions than for community living individuals since residents are accustomed to diverse staff demands which are politely phrased in a question form but clearly imply the expectation of cooperation. Thus, the typical question "would you like to go to dinner, or to see the physical therapist" assumes "yes" for an answer. Hence, researchers must be especially scrupulous in insuring that the institutionalized aged cooperate willingly. We must be aware of an inherent conflict of interest here between the researcher's need for maximizing response rate and the respondent's need for legitimizing noncooperation.

There is also the thorny question of whether ill or impaired older persons have sufficient cognitive ability to provide informed consent. Does disorientation to time, place or person require us to question the meaning of informed consent by such a respondent? There are as yet few clear directives about situations when consent of relatives or responsible persons should be obtained.

C. Sampling

Foremost among sampling issues is that of drawing a valid and meaningful sample. Very seldom is an investigator able to sample randomly using a complete enumeration of the population of patients with the health problem under concern. Usually "samples of convenience" are selected (Watson and Kendall, 1983). Gatekeepers typically make referrals or provide researchers with lists of those persons who, according to administrators, medical personnel or agency staff, meet the study criteria (as defined by the investigators). Selecting patients randomly by accessing actual medical records is seldom the procedure utilized and discretion is this area may rightfully be applied to protect privacy of patients or residents. However, when the process of nomination involves referral, research is potentially fraught with biases which can endanger validity. Four such sources of bias are presented:

1. Survivorship Bias

Since research often focuses on post-illness situations such as caretaking burden, illness adaptation, or morale, samples are comprised of survivors. A most important implication is whether patients who die from health problems are typical or atypical. The authors, in initiating a heart disease study, have found depression linked to heart problems. Yet information as to death rates among depressed heart patients is scanty since studies rarely are conducted in the period immediately following myocardial infarction when most deaths occur.

2. Health Status Bias

Another source of biased data relates to patients' health status. Severity of illness can be a deterrent to participation. In a study of chronic lung disease (Young, 1981, 1982), refusals were common among the most seriously ill emphysemics, particularly those requiring portable oxygen units. "I'm too sick to concentrate" or "I just want to go home and get to bed" were frequent remarks. If research questions involve variables such as post illness adjustment, samples skewed toward those with fewer health problems are likely to cause problems in data interpretation.

3. Health Utilization Bias

Referrals made by health institutions or agencies involve the patient caseloads or clients of those facilities. Therefore, a study of diabetics utilizing lists from a particular foundation will only have a population pool of those who have sought information or services from the agency. Untreated diabetics would be among those eliminated from research, as well as patients who have not accessed the foundation. In studies of ill elderly it should be further noted that the elderly tend to underutilize social assistance programs and services.

4. Special Population Bias

Referral sources sometimes identify persons with certain characteristics. Institutional samples may include an overrepresentation of problem patients perhaps because staff would like to get data on "challenging" cases. Alternatively expressive, verbal well-liked or extroverted persons may be nominated since they may reflect well on the facility. It should be noted that referral sources are generally well intentioned, but biases which are typically unintended and unrecognized do creep in.

IV Research Process Issues

A. Instrumentation

There are few instruments specially constructed for the physically ill elderly. Special stresses of physical illness render certain standardized instruments inappropriate for ill elderly. Problems may range from anxiety brought on by projections about future health to fatigue brought on by excessively lengthy questionnaires. Some of these issues will be further elaborated in our discussion of research procedures with the physically ill elderly.

A major concern in gerontological studies involving physically ill respondents is the lack of availability of instruments standardized for the elderly. Diverse instruments have been developed within the field of medical sociology which relate to illness relevant concerns such as medical compliance, tolerance of pain, etc. (Pritchard, 1974; Pilowsky, and Spence, 1975; Bergner, et al, 1976; Volicer, 1978).

It is tempting to assume that instruments which have been standardized on hospitalized or ill persons would be readily transferable to the elderly (who also frequently suffer from physical ailments). Yet there is ample evidence to indicate that neither form nor content of these measures is readily applicable for use with the elderly. Thus, Likert scales and paper and pencil formats must be simplified and/or converted to interview form when dealing with elderly populations. Furthermore, content related to factors such as impact of illness on work and family; or issues of financing health care must be adapted to reflect the reality of the lives of older persons. Thus e.g., concerns of obtaining transportation to obtain medical care may represent central concerns for elderly patients while threat of losing one's job may be most relevant to younger populations.

In utilizing or adapting existing instruments for use with the elderly, researchers must balance the desire to insure comparability with previous research and relevance to populations of elderly ill.

B. The Interview

The encounter of the researcher with the respondent is usually in a face to face interview situation which can involve structured or unstructured format. Complex interaction takes place in this encounter which can impact on the actual data obtained. In reality there is, or can be mutual impact. Patient illness affects the interview (both process and content) and impacts upon responses given; the interview affects patient health which can influence responses. Particularly of concern are respondents' physical and mental health both as they affect responses to the interview and are affected by the interview process. A model is proposed here which acknowledges the mutual influences whereby patients' health prior to the interview is an input variable on the one hand and the interview process is an input variable on the other hand. Figure one provides a visual representation of the above proposition and indicates that both of these input variables have an ultimate impact on responses patients give to the interviewers. The dynamic nature of the proposed interactions is further elaborated in Figure 2 which introduces a recursive model whereby the mutual influences of patients' health and the interview situation may be simultaneously considered and the impact of the actual patient illness-interview interface on patient responses is depicted. The contextual influences to which we referred earlier in this paper are also included in this model as they are likely to impact on the patient-interview interface. In Figure 3 the model is shown in greater detail indicating suggested components of each of the proposed variables.

Figure 1

Patient Health, Interview and Patient Response

A. Patient Health (physical/mental) → Interview (process & context) → Patient Response

B. Interview (process & context → Patient Health (physical/mental) → Patient Response

Figure 2

Interface of Patient Health, Contextual Factors, Interview and Patient Response

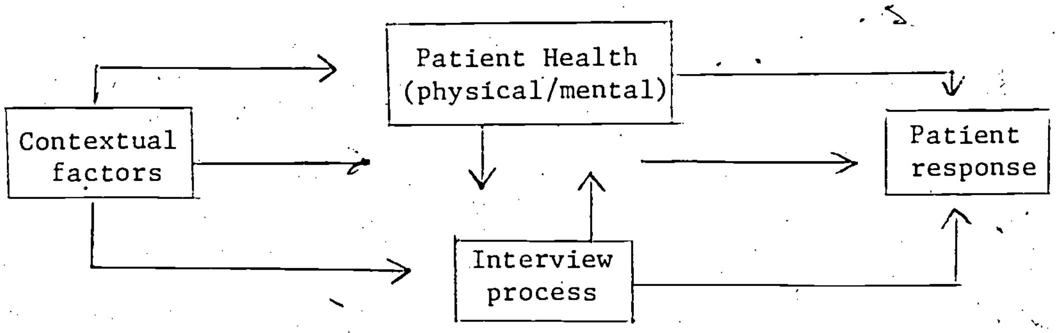
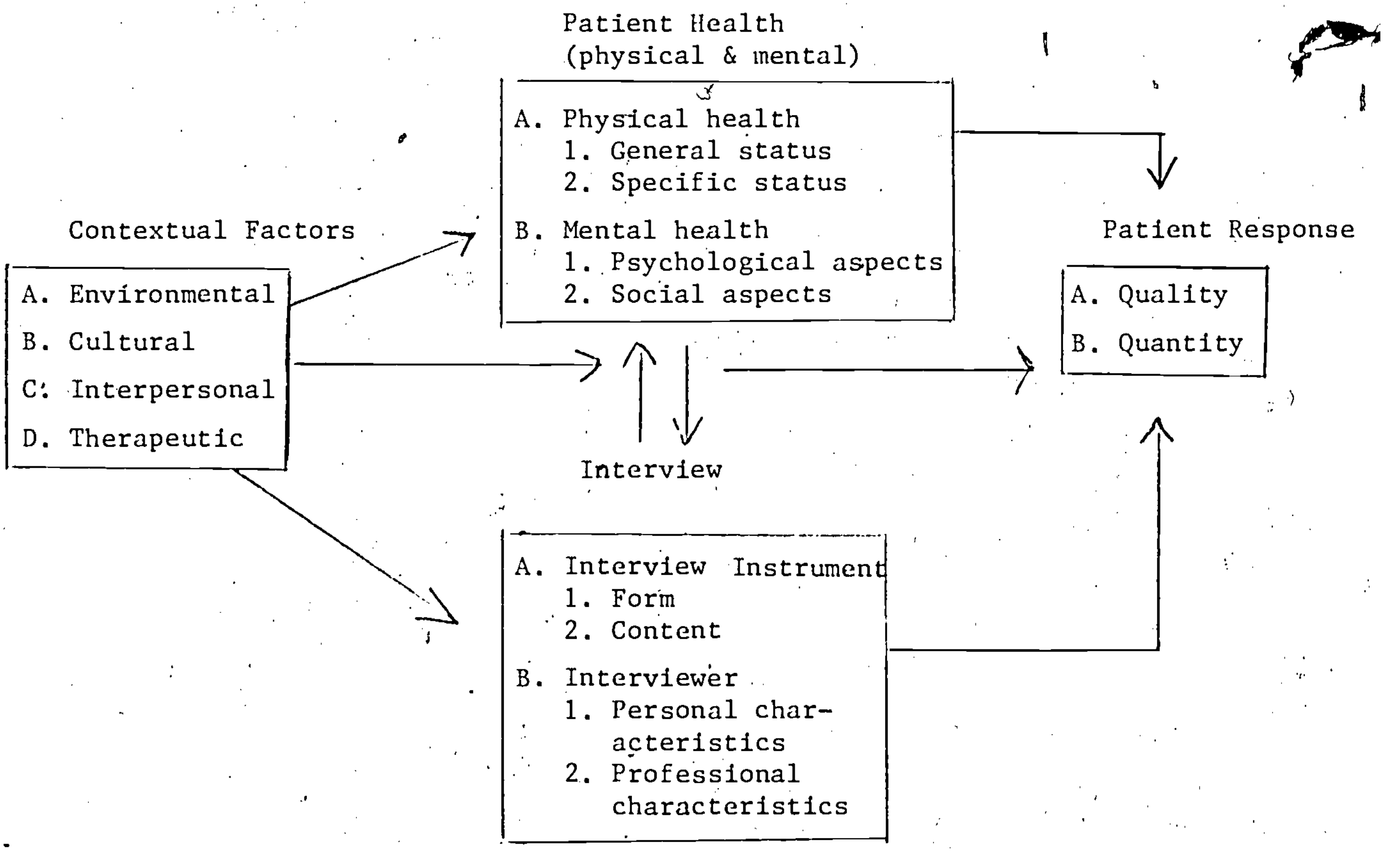


Figure 3

Specified Model of Interface of Patient Health, Contextual Factors, Interview and Patient Response



The model ingredients include physical and mental health of the patient, the interview situation, various contextual factors and patient responses. These elements can interact in simple or complex ways. Physical and/or mental health can act as an independent variable influencing the interview process and patient response. These same factors can be dependent variables as in a situation where data gathering (the interview) proves to be physically or emotionally stressful to patients. Contextual factors can affect physical or mental health of the patient or can influence the interview.

Perhaps the following situations which we have encountered in various community and institutional studies can illustrate the interactions we are proposing.

Contextual factors which inpinge on the research venture can be influential on environmental, cultural, interpersonal or therapeutic levels. The environmental context relating to spatial and temporal aspects of the interview can influence patient health if for example the person is interviewed in a cold room. Cultural phenomena can intervene if the respondents' ethnic heritage encourages stoicism, thereby eliciting health responses which may downplay health problems. The interpersonal context can impact in that it concerns situations where other individuals are present during the interview. If a nurse or attendant is nearby, spontaneity of responses may be affected. Therapeutic elements intervene if patients have been given tranquilizers or similar drugs prior to the interview

Physical and mental health can be envisioned as inputs or outputs vis a vis the research venture. For example, respondents' general or specific health status can govern the response. When interviewing patients with emphysema, breathing problems often necessitate short answers, so questions such as "How would you describe the quality of health care you have received?" are answered in a single word rather than in greater detail. Mental health inputs can be either psychological or social. In the latter case persons who feel stigmatized by a particular health problem can refuse to answer certain questions, envisioning social embarrassment if they do. Coping strategies such as denial of illness are among the psychological inputs which we have found impacting on response.

Physical and mental health variables can also be envisioned as outputs if the process of data collection has health consequences. As is sometimes the case, lengthy instruments exacerbate general or specific health problems. Respondents can get fatigued by the effort required to answer questions, or can experience pain during the interview if medication has worn off.

Psychological state can be affected in many ways. Sometimes the interview generates anxiety. If terminally ill patients are asked about health expectations for the future or those recovering from heart surgery are asked to compare their health with others, these questions may foster an anxious state.

Insofar as the interview situation itself, there are a number of interactions to consider. Personal or professional characteristics of the interviewer can influence the information obtained. A nurse or someone knowledgeable about the health problem can probe about illness matters more effectively than an interviewer who is not a health provider. The form of the instrument may have serious implications for data collection. Since wording of questions, size of print or length of questionnaire can influence response, researchers might want to modify instruments to maximize responses among the ailing elderly.

Patient response has been depicted as the dependent variable in our model. Factors previously presented can affect patient response along qualitative or quantitative dimensions. As some of our examples have shown, the impact may be upon either the amount of information or the degree to which it is reliable or valid. Health problems or contextual factors which act as confounds or mediating variables affect accuracy.

Numerous factors besides those identified can impact on the study. The arduous task specifying all possible contaminating variables is not the purpose of this presentation. Our focus is upon presenting a paradigm which may aid others who are considering influential mediating variables which can confound or otherwise adversely affect results.

V Data Interpretation Issues

Methodological considerations also play a role after collection of data is complete. Sampling issues which have been discussed earlier have important ramifications for generalizability of findings. A major concern is whether findings can be extrapolated to other groups of the elderly since aging health research seldom utilizes random probability samples. Two overarching concerns are: 1) Are results obtained from a sample of older patients with one particular illness applicable to the total population of ailing aged and 2) Can results of a study conducted among a particular group of aging patients be used for prediction purposes among all elderly patients with that physical health problem? With respect to the first, we need to be very cautious in extrapolating results in that health problems as well as their consequences for the elderly are diverse. Even within a category such as chronic illness there are conditions varying greatly in kind and consequence, e.g., sinusitis and emphysema. The second issue concerning applicability within groups is also serious. Examining the case of heart disease, we face the problem of whether persons suffering a heart attack are representative of all heart patients. Differentiation may have to be made between patients with angina pectoris, congestive heart failure, those recovering from heart attacks, and those with multiple heart problems. The symptoms, limitations on activity and prognoses may all differ based on type of heart ailment.

The desire to generalize findings should be carefully examined vis a vis the special methodological problems associated with studies of the ailing aged. Drawing causal inferences or even attempting to generalize descriptive data to populations beyond those sampled can be a risky venture. We must be especially cautious if our findings are used for policy purposes. Although adding to the illness knowledge base is essential, as researchers we need to guard against misuse of our data and the drawing of inappropriate conclusions.

This paper has sought to sensitize both researchers and consumers of research to matters which are central to health and aging studies. Although many of these issues have been implicitly recognized in previous research, in the present work we have tried to be more explicit. We have attempted to delineate the full range of issues and to provide a specific model for considering the interface between patient health, contextual factors, interview and patient response. By specifying research issues for studies of ill elderly, perhaps it will be possible to develop more systematic guidelines for future studies. We have attempted to address issues that all researchers struggle with in the hope that health relevant gerontological research can be streamlined and more accurately reflect the world we seek to understand.

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