

**Special Article**

# A System for Interactive Assessment and Management in Palliative Care

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**Abstract**

*The availability of psychometrically sound and clinically relevant screening, diagnosis, and outcome evaluation tools is essential to high-quality palliative care assessment and management. Such data will enable us to improve patient evaluations, prognoses, and treatment selections, and to increase patient satisfaction and quality of life. To accomplish these goals, medical care needs more precise, efficient, and comprehensive tools for data acquisition, analysis, interpretation, and management. We describe a system for interactive assessment and management in palliative care (SIAM-PC), which is patient centered, model driven, database derived, evidence based, and technology assisted. The SIAM-PC is designed to reliably measure the multiple dimensions of patients' needs for palliative care, and then to provide information to clinicians, patients, and the patients' families to achieve optimal patient care, while improving our capacity for doing palliative care research. This system is innovative in its application of the state-of-the-science approaches, such as item response theory and computerized adaptive testing, to many of the significant clinical problems related to palliative care. J Pain Symptom Manage 2007;33:745–755. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Assessment, computerized adaptive testing, electronic medical records, informatics, item response theory, management, palliative care, psychometrics, practice guidelines, statistical modeling, symptom, respondent's burden*

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**Introduction**

Palliative care has several defining, yet challenging, features that should be prime considerations as the field defines the methods and standards for gathering and using information in research and practice. Palliative care has particularly championed comprehensive assessment,<sup>1,2</sup> because very sick populations

often experience illness-related circumstances in which the patient's mental, social, and spiritual health need to be considered in addition to their physical health. With comprehensive assessment and care, an optimal quality of life can be attained despite serious illnesses. This is the ultimate goal of palliative care.<sup>3-6</sup> Nevertheless, comprehensive assessment can be time consuming for the health care professional. Further, patients often are so ill that stamina is limited, and obtaining information is challenging. In research, as well as in clinical care, this is a serious limitation. Important data may be absent or inaccurate due to patient fatigue or inability to participate. Longitudinal research, like disease and symptom management, can be even more difficult when patients are either too ill to respond, or die before multiple observation points are possible.

Historically, with some notable exceptions,<sup>7</sup> much of palliative care has taken place in small hospice institutions that often use home care and are separate from academic institutions where methodological expertise exists. Because of the limited research available in palliative care, clinical practice standards are still largely based on expert opinions and consensus, rather than on empirical evidence. As hospices begin to engage in the academic aspects of medical research,<sup>7</sup> the concept of population-based research from multiple institutions starts to gather momentum.<sup>8</sup> Developments such as the creation of the National Palliative Care Research and Training Center<sup>9</sup> and the American Academy of Hospice and Palliative Medicine College of Palliative Care<sup>10,11</sup> have created a pressing need and an opportunity to pioneer better methods for information gathering that can properly accommodate the defining features of this type of care, including the broad scope of information available, and the multiple sources from which data can and should be collected.

Another reason for developing a comprehensive database is an inherent difficulty in implementing randomized clinical trials in palliative care. Typically, patients have multiple comorbid conditions; further, suffering is often subjective and difficult to define and measure. Also, studies on seriously ill people may not be feasible, both from a practical and an ethical perspective. Instead, one can learn a great deal from existing variations in the

patterns of palliative care if the processes and outcomes measures are well designed, and if statistical controls are used to eliminate differences due to patient risk factors. Many different studies can be done with little additional cost using a well-designed, archived database.

In this paper, we apply to this challenge a rapidly developing field that we refer to as Clinical Infometrics, the purpose of which is to improve clinical decision making by technology-assisted gathering and processing of real-time, broad-scope, and possibly multiple-source information.<sup>12</sup> We highlight the essential components, derived from the Clinical Infometrics framework, of a system for interactive assessment and management in palliative care (SIAM-PC) that can provide critical information to achieve optimal patient care and to allow for translational research. Different configurations of this system can be tailored for use at the single-institutional level, as well as the multi-institutional, regional, and national levels. Initial implementations of these components are already operational and under evaluation,<sup>13-16</sup> although the entire fully functional system has yet to be implemented in clinical settings. We will describe the overall architecture of the system in an effort to hasten its implementation in a range of iterations at institutions where it can be helpful.

### *System Architecture Overview*

Over the past several years, many research institutions and their affiliated hospitals have developed some form of electronic medical record (EMR) or personal health record (PHR) linked to organized data warehousing capacity for analytic research and clinical guidance. The SIAM-PC builds within many current EMR/PHR systems in several ways but offers extended features and functionalities. It improves the precision and accuracy in gathering patient information through the patient-tailored, adaptive approach, which mimics, but systematizes and makes more efficient, the standard clinical history-taking methods used by the medical profession. As health care computer systems tend to rapidly integrate new technologies, it is necessary to make sure that the systems are flexible and adaptable to the goals of the system.

The SIAM-PC is conceived as a tripartite system (see Fig. 1) consisting of 1) a computerized adaptive testing (CAT) component that administers tailored assessments; 2) a maximum information dynamic database (MIDD) component that houses assessment data; and 3) a clinical decision support system (CDSS) component that aids clinicians in making diagnostic and therapeutic decisions in patient care.<sup>17</sup> Fig. 1 also depicts how multiple sources of information from clinicians, patients, and caregivers can feed into the SIAM-PC through the use of CAT.

The design of the SIAM-PC allows questions and responses to be transmitted and retrieved by whichever front-end assessment media are available—telephone, computer, handheld device—with the information input contributed by multiple parties. For example, a patient may enter data by telephone at home, or a clinical assistant or nurse may type in data to a computer terminal in the clinic. Data can then be securely transferred to a central back-end server (or data warehouse, which we have named MIDD) through mobile and fixed telecommunication technologies. These data can be analyzed in multiple ways, including prevalence reporting, benchmarking, and causal and predictive modeling. Meanwhile, the CDSS interprets the patient-related data in real time, as it compares patient information to clinical practice guidelines (based on research performed using the MIDD) to create advisory guidance that can be used by

clinicians, caregivers, and patients to assist clinical decision making.

The SIAM-PC is also designed for multiple users, as the patients, their caregivers, or their clinicians can enter information about the patient (or about the caregiver or any other relevant component of a comprehensive assessment), and each party can receive appropriate and timely medical guidance. This latter feature is important for palliative care, which as its hallmark emphasizes the interdisciplinary team and the inclusion of the patient's family in the plan of care.

The first step in using a CDSS is entering the patient-related data, which is done by the clinician, patient, or caregiver. After the data entry, scores on an array of measures (e.g., quality-of-life domains) are calculated and paired to other clinical and demographic characteristics. These are then compared, using prognostic/diagnostic models, to parameters in clinical practice guidelines and population characteristics. The third step is the production of feedback that assists clinicians in their medical decision-making process and offers the caregiver/patient useful recommendations. Because feedback is given to different groups of individuals, it must be tailored to the language and knowledge level of the recipient, be it the physician, nurse, or other health care professional (formal health care), the caregiver (informal care), or the patient (self-care). All output from the CDSS must also be aligned with the cultural norms and existing information networks of the environment into which it is released.

The SIAM-PC is designed to allow for evaluation and adjustment of the questions being asked. The MIDD portion of the system, which houses the data that are collected, can be engaged to test whether the information gathered by the CAT system is sufficient, as well as to evaluate whether the clinical advice provided by the CDSS is in accordance with state-of-the-science, evidence-based medicine.

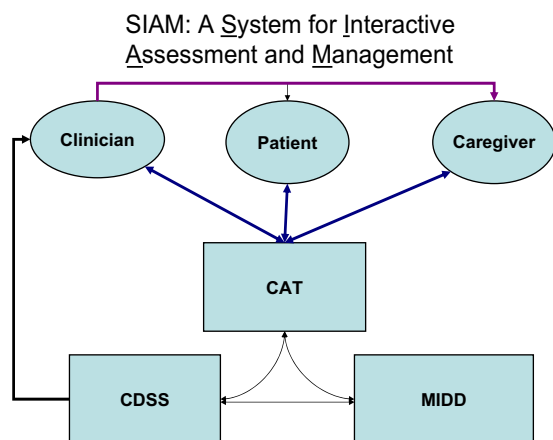


Fig. 1. The SIAM-PC architecture. CAT = computerized adaptive testing; CDSS = clinical decision support system; MIDD = maximum information dynamic database.

### ***Challenges to the Implementation of the SIAM-PC***

#### ***Regulatory and Legal Concerns***

To comply with patient privacy regulations, largely encompassed by the Health Insurance

Portability and Accountability Act, patients/subjects will need to agree, probably by signing a waiver, to use of the data for research purposes, including the entry of such information into a pooled database such as the SIAM-PC. Consent should include permission to use at least until the patient's death, and possibly afterward, so that longitudinal data can be collected. Researchers who use the database will have to complete the necessary Institutional Review Board clearances.

### *Methodological Concerns*

Because SIAM-PC allows for data to be obtained from patients, family members, and clinicians, individuals using the data in the MIDD will need to make analytical decisions on how to reconcile potential differences in the data obtained from multiple sources. To some extent, these problems can be dealt with by using advanced statistical methods, triangulation, and other approaches.<sup>18,19</sup> To understand the limitations of the data analysis, researchers should be made aware of the methods used for reconciliation.

### *Components of the System*

The SIAM-PC has several different processes. Table 1 summarizes the key processes and lists potential technologies for their implementation, and a discussion of each follows.

#### *CAT Component*

Traditionally, most surveys and assessments are done using fixed-length questionnaires

that require the respondents to answer all of the questions. Some tests or surveys use skip patterns to avoid asking unnecessary items and to probe when responses to items indicate the need for deeper inquiry. These methods are effective, but they are still labor intensive and require training of those who administer the questionnaires to achieve necessary levels of standardization. In CAT systems,<sup>20-22</sup> the computer is programmed to select items that are as informative as possible and lead to optimal use of subsequent items. These algorithms occur at each stage of item selection. The CAT decision rules reduce the possibility of a human error, and can reach a given level of measurement precision more quickly than one can using a test in which all test recipients are administered the same full set of items. CAT systems reduce the number of items that need to be administered (typically 50% or more) with no decrease in measurement quality, making CAT systems both efficient and effective.<sup>23</sup>

#### *Item Bank Construction:*

##### *Item Collection and Reduction*

Development of a patient-tailored algorithm for the CAT approach to comprehensive palliative care assessment first requires the establishment of a bank of items that have been selected for that purpose. Item response theory (IRT)<sup>24,25</sup> provides methods particularly well suited to determine which questions/items will produce the greatest amount of information with a minimum effort for comprehensive patient assessments. The IRT is a statistical theory consisting of mathematical models expressing the probability of a particular response to

Table 1  
Key Processes and the Technologies That Can Achieve These Processes

Key Process	Technology
A. Use of standardized assessment tools from multiple-source tools	CAT system
B. Item bank construction: item collection and reduction	IRT
C. Developing a logical skip-pattern approach	Unfolding patient-tailored algorithms and planned imputation based on IRT
D. Administration of test items	Algorithms for scoring and selecting items are integrated into the system. The computer continually updates the person's estimate of the domain being measured using IRT methods
E. Planned evolution of the CAT component	Accommodation is made by adding new items into the bank of items in the database portion of the system, MIDD. The CAT system tests new items to add to the roster of items
F. Consolidation of all component data elements	MIDD

a test question (or survey item) as a function of the quantitative attribute (latent “unobservable” trait) of the person, and of characteristics (parameters) of the item.<sup>24,25</sup> The IRT models have been routinely applied for many years in educational testing, both to measure ability or proficiency in an efficient fashion and also, in psychological assessment, to measure personality traits. Over the past decade, the use of IRT models in patient-reported assessment has grown considerably.<sup>26,27</sup> In palliative care, the latent trait that we wish to measure would be defined by a particular area of potential suffering, such as pain, depression, or financial burden.

The creation of a comprehensive item bank for palliative care is a multistep process. An item pool or a universe of items is first compiled from existing evaluation instruments or questions used in clinical practice. The IRT-based analysis is then performed on the responses to these items to identify which are the most information-rich items. These items are then presented to palliative care experts for clinical approval. Within limits, it is also possible at this point in item bank construction to include other items that are deemed clinically necessary. The resulting items are then partitioned into subsets of questions or “booklets” using factor analytic methods to represent each of the themes of palliative care. A “booklet” is a set of items that screen and evaluate the subject within a particular theme or domain (e.g., physical functioning or pain).<sup>28,29</sup>

#### *CAT as an Improved Version of Unfolding Patient-Tailored Algorithms*

Some assessment tools have used a developed version of the skip-pattern approach, commonly used on surveys, allowing the instrument to emulate more closely the traditional history taking and management methods that clinicians have developed by convention. We call this the unfolding approach. Taking a patient’s medical history is a refined approach that has evolved from experience and has been codified in teaching and in textbooks. It is less of an empirically guided or scientific approach. The unfolding approach offers a method by which the challenges of comprehensive assessment can be empirically driven. An initial version of the unfolding approach

can be explored using factor analysis, rather than IRT, and a paper and pencil, rather than CAT.<sup>30</sup> The unfolding approach therefore provides an opportunity to compare and assess traditional history taking, as well as an opportunity to integrate information gathering with management suggestions in an empirically driven design.

In an unfolding approach, the patient or subject first responds to a set of high sensitivity items (i.e., anchor questions) that screen for the presence of a problem in a broad domain. If there is no evidence of a problem from the respondent’s answer, then a score or rating for that domain will be calculated based on normalized population averages, and no further items from that same domain will be asked (i.e., other items in that domain will be skipped). If there is evidence of a problem, the next layer of questions, which often have a higher specificity and lower sensitivity, is engaged. This process will continue until the most specific questions have been answered for all areas where a problem exists.

Starting and stopping rules have to be pre-defined with practical considerations. This type of approach has already been introduced in the field of palliative care, with instruments such as the needs near the end-of-life care screening tool (NEST), multidimensional aspects related to caregiving experience (MARCE), and resident assessment instrument for palliative care (RAI-PC) series. The NEST is an instrument that seeks to systematize the skilled clinician’s approach for comprehensive assessment of palliative care patients.<sup>30</sup> The MARCE, still under development, does the same for caregiver assessments,<sup>31</sup> while the RAI-PC does the same for patients in long-term care settings, but with more emphasis on research applications.<sup>32</sup>

For an example of how the unfolding process works, one could develop algorithms for screening based on NCCN Practice Guidelines in Oncology. A patient may be asked to respond to an appropriate screening question in a “psychological distress” subdomain. If the patient responds “no” to a valid screening question, this allows the clinician to move on to the screening question in another subdomain (such as physical pain) with confidence that psychological distress is not a problem for this patient. Alternatively, if the patient

responds “yes” to the screening question for psychological distress, then the clinician would be directed to inquire further, using more specific questions to determine more precise needs. The patient’s response to the more specific items would guide the clinician to the appropriate overall plan of care. In this case, that could include an evaluation of whether a referral to social services is needed to assist with mobilization of family, community, or financial resources.

In SIAM-PC, as in NEST and other instruments, items will often form scales. Cut-off scores or termination criteria can be used to determine how CAT proceeds to another evaluative question or to another theme or domain or stops. Overall, as helpful as the unfolding approach may be, SIAM-PC offers an improvement analogous to the improvement offered by CAT over linear paper-and-pencil educational testing, since the CAT, which is based on IRT, computes item selection efficiently through the use of booklets. This means that only maximum information items need to be used. This allows CAT to simulate and, in great part, replace the more laborious unfolding instruments, as well as the clinician’s history taking.

The proposed method of data collection creates a set of comprehensive information on all subjects by relying on intentionally skipping questions that are not applicable. While a data structure of the questions being administered may vary from individual to individual because of the skipping patterns, all domain-specific and total scores for the domains across all individuals are comparable and available for medical research. Individual items that are skipped during the data collection phase are coded accordingly and distinguished from typical nonresponse to items that result from fatigue or other factors.<sup>33</sup> An intentionally nonadministered item carries information in the sense that an inference is made based on IRT that responses to it would indicate no clinical problem. This type of planned imputation based on IRT is different from imputation methods used for missing data that result from respondent’s dropout, refusal, or other factors.<sup>34,35</sup> The collective information from all individuals, therefore, holds information in an analogous way to a data set in which responses to items may be gathered in one of

two ways, but all available items have response-equivalent information. Specifically, research based on data from the MIDD would be as reliable as if it were obtained from a full, linearly administered questionnaire.

#### *Administration of Test Items*

In the last two decades, software for implementing IRT-based CAT has been developed and improved, and some aptitude and certification tests such as the Graduate Record Examination now use the CAT systems. The feasibility and acceptability of administering these programs in the educational and clinical settings have already been demonstrated.<sup>36–38</sup>

The palliative care CAT, in the SIAM-PC setting, proceeds by domain, as described above. Algorithms for scoring and selecting items are integrated into the system, and typically another item is selected for administration and presented on the screen immediately after a response is given to the previous item. Meanwhile, the computer continually updates the person’s estimate of the domain being measured, again using IRT methods, and continually monitors the appropriate termination criterion (e.g., a certain level of precision for all target domains). Once the termination criterion is reached, the test ends.

Support of multiple delivery platforms for the CAT system is necessary because of the diversity in patients’ locations at the time of input (say for quality-of-life information from home and new symptom information from the waiting room at the doctor’s office) and because of the need for potential input by multiple respondents (physician, nurse, family caregiver, social worker, pharmacist, pastor, etc.). In addition, multiple types of platforms for data entry are necessary to accommodate the capacity of a full range of patients. Although Web-based systems are becoming popular because of the ubiquity of the Internet, the reach of the Internet still cannot match to that provided by telephones, including cell phones, especially for the elderly and low-income families who do not possess resources or who still feel uncomfortable with new technologies. An interactive voice response (IVR) system using existing phone access provides what may be a more acceptable communication platform for some patients. Telephony or IVR, similar to Web-based approaches,

provide acceptable ways to collect assessment data either prior to the office visit or as a follow-up without committing additional staff time.<sup>39</sup> For those patients who have strength or mobility limitations, a portable computing device such as a Tablet PC or handheld device would be the quickest way to collect assessment data. Portable devices are also suitable for use in waiting/exam rooms and for providers visiting patients at home.

#### *Planned Evolution of the CAT Component*

The SIAM-PC must be able to accommodate changes in practice standards as medical research progresses. This accommodation is made by adding new items into the bank of items in the database portion of the system, MIDD. The CAT system tests new items to add to the roster by initially administering but not scoring the item in order to evaluate its performance. Additional information on randomly selected patients is gathered so that these new items can be calibrated with the existing items.

#### *MIDD Component*

All the information gathered by the CAT is populated to a database that we call the MIDD.<sup>32</sup> Researchers using the MIDD will face the usual issues that arise whenever multiple large databases are used. Because SIAM-PC allows for data to be obtained from multiple sources, the users of the data in the MIDD will need to make analytical decisions on how to triangulate and reconcile or use the difference between data from multiple sources, as explained earlier in this discussion.<sup>18,19</sup>

### ***Uses for the SIAM-PC System***

#### *To Improve Prognostication in Different Clinical Circumstances*

A second challenge of palliative care research is the short prognosis that patients often have. This prognosis is difficult to estimate accurately for any individual.<sup>40</sup> Large databases, such as the MIDD in SIAM-PC, can be used to estimate propensity scores for patient survival in a very sick population. While longevity for a particular patient is inherently difficult to predict, the likelihood (propensity) of death happening in a given period of time can be estimated accurately, given a set of

prognostic factors (i.e., covariates, based on population data). Researchers can use this information in various ways. For instance, frequency of data gathering at a given point in time can be scheduled in intervals inversely proportional to the propensity of death as a strategy to reduce the probability of incomplete data due to a subject's death. Such a strategy might be coupled with the use of a limited number of high information items to minimize respondent's burden as the patient gets sicker and sicker.

#### *To Facilitate Longitudinal Research*

The novel data structure of the MIDD also allows for the conduct of longitudinal research. Longitudinal data collection could be built into the structure of the database to the extent that such information is available for subsets of the population included in the system. This can be done using a relational database structure, so that variable length records could be part of the system. These longitudinal records could also be flagged according to different parameters of interest, such as the time sequences for which data are recorded.

An advantage of longitudinal data is that one could follow patients over time to observe various patterns in symptom development and control. For example, it may be possible to use longitudinal data to gain a better understanding of how to control breast cancer pain by studying the trajectories of women who are diagnosed at a later stage, and observing the patterns of pain over time, by the stage at diagnosis, and patient age and race. Such findings could lead to better pain control for women with advanced stage breast cancer.

#### *A CDSS*

A CDSS is a computer program or set of programs that provides reminders or clinical advice specific to a given patient based on information entered into the system. The CDSS component of the SIAM-PC includes the following elements:<sup>18</sup>

- a user-friendly interface for the clinician, patient, and caregiver;
- a reminder system that activates designated items generated from MIDD based on clinical consensus or empirically determined response thresholds;<sup>33</sup>

- a decision-making software that makes use of capabilities such as neural networks and inductive tree methods;
- case-based reasoning to allow patient information to trigger recommendations, clinical guidelines, and consensus standards;<sup>18</sup> and
- a mechanism for updating CDSS recommendations and integrating these updates with equivalent updates to items in MIDD and CAT.

The first step in using the CDSS is entering the patient-related data, which is done by the clinician, patient, or caregiver. After this, scores on a variety of measures, such as pain, will be calculated and paired to other clinical and demographic characteristics. These will then be compared, using prognostic/diagnostic models, to parameters in clinical guidelines and population characteristics. The third step is the production of feedback that assists clinicians in their medical decision-making process and offers the caregiver and/or patient useful recommendations. Because feedback goes to different groups of individuals, it must be tailored to the recipient's language and knowledge level, as well as cultural norms and information networks. For instance, recommendations about how to communicate serious news should be tailored as best as possible to the situation, including information about how the patient and his or her family prefer to handle information. Similarly, recommendations to seek support groups through a professional association's Web site are not too helpful for communities in which Internet use is rare.

An example of how the process might work is as follows. An elderly woman with disseminated breast cancer who receives hospice care generally enters information about her condition over the telephone from home. One week, she registers a high pain level even while taking pain medications that were previously prescribed. The CDSS will note this and produce in real-time output for the physician or nurse suggesting that there may be inappropriate medication use, the current medication may not be effective in controlling the old source of pain, or there may be new pain to address. If the problem is more specifically identified, clinical guideline-derived

courses of action will be suggested and the clinician can decide to evaluate this information and act according to his or her professional judgment. Information on the clinical care provided can also be used and analyzed by researchers to evaluate the quality of guidelines that are used by the CDSS and the quality of care rendered by clinicians.

#### *Data Source That Can Be Used for Creating New Evidence-Based Clinical Guidelines*

The MIDD will allow researchers to examine a variety of research questions about end-of-life care, but it will also lay the groundwork for the creation of evidence-based clinical guidelines. Currently, clinical guidance is based primarily on expert consensus rather than on clinical evidence, and there is a need to move standards from their consensus basis to an evidence basis. The SIAM-PC has the capacity to distill comprehensive patient information and link it to clinical guidance that can then be systematically studied in rigorous randomized controlled trials.

## **Discussion**

### *Implications of CDSS Combined with Modern Technologies*

The CDSS represents a confluence of technology, methods, clinically appropriate programs for information gathering, and user capability that allow a transformation in many spheres of life. This is particularly useful for populations of people who are hard to reach or who have difficulty accessing services. With cost coming into a range such that it is conceivable to disseminate information technology devices even in resource-poor settings, a range of options can be offered. At the lower-cost end, palm-held devices that are suitably programmed to take a lay person through a medical history could be widely available in homes so that the patient or caregiver could communicate information to a clinician far away, allowing the virtual home visit to take on realistic efficacy. This would change the nature of the patient-caregiver-clinician relationship and could follow in the trend toward more community-based health care models, with empowerment of patients and caregivers. Other allied health providers, such as social

workers, pastors, pharmacists, counselors, and occupational or physical therapists, can also be included as part of the interdisciplinary team so that care can be better coordinated through the sharing of information and a standardized decision-support system. These changes, as significant as they may be in a technically developed and resource-rich setting, could be revolutionary for medical care of people who are in less developed and poor settings. Finally, although SIAM-PC is designed specifically to accommodate the defining features and challenges inherent in palliative care, we recognize that a similar system for interactive assessment and management could be used for most fields of medical care and even beyond medical care.

### *Potential Barriers*

In light of the potential usefulness of the SIAM-PC, we also realize some of its limitations. First, as with any large database or complex system, the SIAM-PC will demand potentially labor-intensive management, such as setting up the necessary infrastructure and protecting data privacy in accordance to regulations. However, these are unlikely to differ significantly from other complex systems, and the potential benefits of improving quality of care and research will be great. Second, as described in the MIDD component section, the nature of the data collected by the SIAM-PC will be unique, as there will be varying patterns of intentionally skipped questions. This will require that researchers be trained in analyzing such data and drawing appropriate inferences and conclusions concerning questions related to end-of-life care. Finally, those wishing to establish the SIAM-PC in their medical institutions must achieve buy-in from the relevant leaders and stakeholders, and should modify elements of the SIAM-PC to fit into the existing clinical culture and environment.

The data in the MIDD provide information for clinical and epidemiological researchers. Administrators of SIAM-PC should be able to offer guidance, based on the researchers' description of their research project, about data needed for it and any relevant and special features of SIAM-PC. Because individual items within each domain (or booklet) may be missing due to the intentional skipping patterns of the questioning, this may limit the types of

research questions that can be investigated using the SIAM-PC; however, instead of analyzing individual items separately, overall domain scores can be analyzed as part of the total-patient assessment. For instance, while mental health as a general domain for an end-of-life population can be investigated, a specific item in the mental health "booklet," such as one on depression, may not be possible if the item has been intentionally skipped for several individuals in the data set. In situations where researchers wish to obtain and analyze individual items, especially those that were intentionally skipped, administrators responsible for the MIDD component of the SIAM-PC should work with or share design information with the external investigators to allow for appropriately devised advanced statistical methods to sufficiently handle the potentially missing data.

### *Conclusions*

We have sketched out the system architecture of a SIAM-PC, which is a response to the challenges found in palliative care. The advances that the SIAM-PC makes in these areas are also broadly applicable to other populations and conditions, but we propose this system for a population with significant needs and challenges. The SIAM-PC's CAT component lessens the burden on patients and those who care for them by streamlining comprehensive assessment. The MIDD component possesses unique data for a population database that will be useful to researchers conducting longitudinal and other studies, which have to this point been difficult to conduct in the field of palliative and end-of-life care. Finally, implementation of a CDSS, perhaps in later phases of the SIAM-PC, has the potential to improve quality of care by health care professionals, caregivers, and patients themselves.

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