

Self-report of Cancer-Related Behaviors

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Self-report data are essential to behavioral research and clinical practice.

Self-report is one of the primary means of obtaining information about a person, placing it at the heart of the research history that underlies much of cancer diagnosis and care. There are numerous benefits of retrospective self-reports, such as the expeditious development and modification of measures that are easy to administer and complete. Indeed, **self-report is often the most cost-effective and valid means of collecting personal information** (Baker & Brandon, 1990; Stone, Shiffman, & DeVries, 1999). Assessment of cancer-related behavior via self-report shares these strengths, although **there are also limitations inherent to the use of self-report methods.**

Behaviors (and their predictors) influencing cancer risk are often individual difference variables that require self-report (e.g., number of cigarettes smoked daily) or are constructs that cannot be readily observed (e.g., emotional experience, motivation towards preventive care). Although some behaviors have a gold standard that can be employed to test validity (e.g., tobacco use, some screening behaviors), for many other behaviors there is less clarity, ease, or a gold standard is not available (e.g., eating a nutritious diet, symptoms such as pain and fatigue). Improving the accuracy and utility of self-report measures would advance cancer research and clinical practice. We attempt to provide an overview of this issue by reviewing several key domains in the self-report of cancer-related behaviors.

Self-report of Cancer Behaviors

Over the past 50 years, cancer research has emphasized individual behaviors (e.g., early detection screening, smoking, alcohol use, diet and nutrition, and physical

activity) as important foci for prevention (Hataway & Bragg, 1984). Self-report instruments are among the primary methods of assessing cancer-related variables, including early detection screening and behavioral risk factors (primary prevention), as well as psychosocial risk factors (secondary and tertiary prevention). This section discusses self-reported cancer screening and considerations for the use of self-reported behavior and psychosocial risk factors, and concludes with suggestions about how to most effectively use and interpret self-report data.

Self-reported cancer screening. Cancer screening is a commonly reported clinical assessment designed to facilitate early detection, and regular screening is important for reducing morbidity and mortality across an array of cancer types.

Although more objective alternatives exist for determining screening practices in the population (e.g., health insurance or medical records), self-report of screening is nonetheless the measure of choice in the majority of studies. For example, about two-thirds of research examining Pap smear testing utilized self-report methods (Newell, Girgis, Sanson-Fisher, Savolainen, & Hons, 1999).

With the growing emphasis on preventive care, a body of research has tested strategies aimed at encouraging patients to be screened in accordance with recommended guidelines (e.g., Masi, Blackman, & Peek, 2007). Although increased screening is not universally recommended, efforts to promote screening are common – including, but not limited to, screening for breast, cervical, ovarian, colorectal, and prostate cancers. **Self-report validity studies often report kappa (i.e., percent agreement), sensitivity (i.e., true positives—the proportion of participants screened according to objective markers who self-reported the screening), and specificity (i.e., true negatives—the proportion of participants not screened**

according to objective markers who self-reported no-screening). Concordance rates for medical records and self-reported data indicate that **the prevalence of cancer screening is overestimated by self-report** (Gordon, Hiatt, & Lampert, 1993; Hiatt et al., 1995), **whereas the time since the most recent test is underestimated** (Gordon et al., 1993). Research in other areas has found that people can often accurately report the day of week a given event occurred, yet they tend to report a more recent date than actually was the case (Cohen & Java, 1995; Thompson, Skowronski, & Lee, 1988). This may occur because greater clarity of a memory provokes feelings of recency (Bradburn et al., 1987). Along these lines, people tend to anchor their reports to reasonable timeframes and/or round the values off to the number of weeks or months (Huttenlocher et al., 1990). Each of these lines of **evidence suggests that report of specific dates or the duration of time passed since an event may be inaccurate.** The sources of these biases are unclear, but they likely reflect individuals' reliance on schemas when answering temporally-based questions.

Although findings are mixed, the utility of self-report data for some specific types of screening is promising. Some research has found high sensitivity and agreement for breast and cervical cancer screening (Caplan et al., 2003), although other research has not (Bowman, Redman, Dickinson, Gibberd, & Sanson-Fisher, 1991; Bowman, Sanson-Fisher, & Redman, 1997). Lykins, Pavlik, and Andrykowski (2007) concluded that **the validity of self-report for determining routine ovarian cancer screening (i.e., transvaginal sonography; TVS) was very high when compared to medical records.** Indeed, their evidence suggests that TVS self-reports are more accurate than breast, cervical, and colorectal cancer screening reports.

Despite these encouraging findings, however, **accuracy of self-reported mammography and Pap smear testing for clinical decision-making may be lower among low socioeconomic, underinsured, and/or minority groups** (McGovern, Lurie, Margolis, & Slater, 1998; McPhee et al., 2002; Vacek, Mickey, & Worden, 1997). Fewer studies have examined the use of **self-report for colorectal or prostate cancer screening, but existing evidence suggests high (Bleiker et al., 2005), or fair to moderate concordance with medical records (Hall et al., 2004; Jordan, Price, King, Masyk, & Bedell, 1999).**

Overall, research suggests that patient self-reports of cancer screening are reasonably valid. However, the precision of estimates of timing are considerably less reliable (e.g., specific dates or the time since the most recent screening). It is important to note, however, that patient reports are not always intentionally biased. For example, several types of screening can be conducted as part of a full examination, leaving patients unaware that a particular test was conducted (Hall et al., 2004).

Self-reports of cancer risk behaviors. Cancer risk is elevated by the presence of both uncontrollable and controllable risk factors. Self-reports are used to estimate the prevalence of risk factors in the population and the efficacy of interventions seeking to reduce them. Risk factors that are beyond one's control generally include family history/genetics, race/ethnicity, prior history of cancer, and age. However, there are a number of controllable risk factors that are related to behavior, such as smoking, heavy alcohol use, poor diet/nutrition, physical inactivity, ultraviolet light exposure, and risky sexual behavior. A complete review of the nature of self-reports of these factors is beyond the scope of this discussion; rather, our aim is to consider several key variables related to cancer risk, and to briefly describe evidence

for the validity of their self-report. Newell and colleagues (1999) conducted a comprehensive review of the accuracy of self-reported health behaviors and cancer-related risk factors. They found that, in general, self-reports consistently underestimated risk factor prevalence and percentages of 'at-risk' individuals.

Tobacco smoking is the leading cause of preventable cancer morbidity and mortality, making smoking status into one of the most commonly reported cancer-related risk factors. Earlier research revealed a tendency for smokers to underreport (e.g., Haley & Hoffman, 1985) or deny their smoking completely (e.g., Luepker, Pallonen, Murray, & Pirie, 1989; Murray, O'Connell, Schmidy, & Perry, 1987). More recently, however, evidence suggests that smokers are willing to self-disclose this behavior. Patrick and colleagues (1994) found that **the overall validity of smoking self-reports is high, with sensitivity and specificity estimates of close to 90%. Self-reports of cigarette smoking also appear to be valid among adolescents across racial/ethnic groups** (Kentala, Utriainen, Pahkala, & Mattila, 2004; Wills & Cleary, 1997). Some recent work, however, suggests that the accuracy of self-reports may be declining, perhaps in conjunction with the underreporting of illicit drug use (Fendrich, Mackesy-Amiti, Johnson, Hubbell, & Wislar, 2005).

Clinical trials using self-reported smoking abstinence as an outcome should follow recommended definitions (c.f. Hughes et al., 2003). Whenever possible, **researchers should biochemically validate smoking status using gold standard markers, such as carbon monoxide (CO), salivary cotinine, or thiocyanate.** Researchers should also consider the possible role of social desirability in smoking status reports. In particular, **certain types of smokers may have a higher likelihood of underreporting, including those with chronic diseases (Fisher, Taylor, Shelton,**

& Debanne, 2007), pregnant women (Russell, Crawford, & Woodby, 2004), and hospital inpatients (Schofield & Hill, 1999).

Heavy alcohol use is associated with elevated cancer risk (Cargiulo, 2007). **The gold standard for biochemical verification of short-term alcohol use is a breathalyzer test;** yet this test is infrequently used in research (see Newell et al., 1999). Grønbaek and Heitmann (1996) found overall agreement between self-reports on an alcohol use frequency questionnaire and dietary interviews. However, the number of studies that carefully examine the validity of self-report of alcohol use is not yet adequate to form firm conclusions. Even in the absence of biochemical verification, the **“bogus pipeline”** (a procedure that induces the [false] belief that drinking will be biochemically verified; e.g., Botvin, Botvin, Renick, Filazzola, & Allegrante, 1984; Campanelli, Dielman, & Shope, 1987; Jones & Sigall, 1971) can increase the accuracy of self-reports of alcohol consumption in clinical or research settings.

Physical activity levels are also commonly estimated in cancer prevention studies. Reporting levels of physical activity is challenging for several reasons. Respondents are asked to recall many separate events over a period of time, some of which may not be particularly salient or memorable (e.g., walking). Recall is also more difficult when respondents report both duration and intensity of each activity. In addition, the categories of physical activities defined in surveys (e.g., the Seven Day Activity Recall questionnaire; Sallis, Buono, Roby, Micale & Nelson, 1993) require respondents to make judgments about what constitutes moderate, hard, and very hard activities. Sallis and colleagues (1993) found lower reliability for repeated reports from longer intervals (4–6 days between interviews) versus shorter intervals, suggesting rapid decay of subjects' ability to remember specific physical activities.

There are a number of **approaches to objectively assess the validity of self reports of physical activity**, including: **mechanical or electronic monitors** (including accelerometers and heart rate monitors), **energy expenditure** (including doubly labeled water and calorimeter), **measures of fitness, and direct observations** (Kohl, Fulton & Caspersen, 2000). These types of measures, however, correlate rather weakly with self-report (Sallis & Saelens, 2000), although this weak relationship may be due in part to devices such as accelerometers missing some light and moderate activities (Richardson, Leon, Jacobs, Ainsworth & Serfass, 1995). Similarly, self-reported data on physically demanding activities are well-validated using heart-rate monitors, but lower correlations between self-reported physical activity and heart rate have been found for less intensive activities (Janz, Golden, Hansen & Mahoney, 1992). Overall, **reliance on the accuracy of physical activity reports may be acceptable for specific activity frequencies (e.g., frequency of tennis) or gross activity (e.g., sedentary versus not), but far less reliable for any specific intensity measure (e.g., total time spent exercising, percent of activity at VO₂max, etc).**

There is a long history of research relating cancers to **dietary factors** (e.g., Doll & Peto, 1981), but evidence for a causative role of diet in most cancers is limited. That is, epidemiological studies have identified relationships between dietary practice and cancer development, but prospective or interventional studies have often not provided strong corroborative support. High-fat diets appear associated with increased risks of breast, colon, prostate, and endometrial cancers (USDHHS, 1988). Diets high in salt and red/processed meats have been linked with stomach and colorectal cancer, respectively (Key, Allen, Spencer, & Travis, 2002). In contrast, high fiber diets are

related to reduced risk of colon cancer (Trock Lanza, & Greenwald, 1990).

Unfortunately, **there is no established gold standard for the measurement of diet or nutrition, leaving self-report methods open to include daily or weekly diaries, clinical interviews, and portion-size estimates.** The latter approach is less frequently used and appears to offer little incremental validity to diet-related risk assessments (Paiva, Amaral, & Barros, 2004). Much research has employed **food frequency questionnaires (FFQs)**, which ask respondents to indicate their “usual” food intake over a weekly, monthly, or yearly reference period (e.g., Zulkifli & Yu, 1992). Cavadini and colleagues (1999) found good agreement between an FFQ and “diet records” collected by experience sampling methods (see later section), although the level of agreement varies widely by type of food. However, diet records are not consistently in good agreement with an objective measure such as **doubly labeled water (a method in which participants drink treated water that allows for measuring metabolic rate over days or weeks;** Livingstone et al., 1992). Indeed, **studies have found substantial underreporting of food intake in diet records among obese participants, female endurance athletes, and adolescents** (Schoeller, 1995). These studies suggest that diet records themselves should not be used as independent methods of validation of FFQs. Other studies have found **24-hour recalls obtained via interview with a dietician provide more accurate estimates** (e.g., Field et al., 1998; Frank et al., 1992; Rockett et al., 1997).

Obesity is an established risk factor for some cancers (colon, breast, endometrial, and possibly other cancers; e.g., Trentham-Dietz, Nichols, Hampton, & Newcomb, 2006; Verreault, Brisson, Deschenes, & Naud, 1989), making it important to accurately assess obesity and body fat distribution. **Body mass index (BMI), or the**

ratio of weight to height, is often reported in epidemiological research. Although there is a tendency for overestimation of height and underestimation of weight, **there is evidence for the validity of BMI self-reports** (e.g., Palta, Prineas, Berman, & Hannan, 1982). Body fat distribution is measured in a variety of ways, but one easily implemented measure is waist-to-hip circumference, also referred to as **waist-to-hip ratio** (WHR). Weaver and colleagues (1996) found that WHR can be measured accurately by self-report when respondents are provided with all the materials needed to conduct the measurements and are given explicit instructions and training. Even under these more optimal conditions, however, women with larger WHR are likely to underestimate their measurements when compared with clinic-based assessments (Weaver et al., 1996).

Self-Reports of Family History

Family history of cancer, particularly first-degree relatives, is a factor associated with increased cancer risk (e.g., Issacs, Kiemeney, Baffoe-Bonnie, Beaty, & Walsh, 1995). **Self-report is the primary method of assessing family history of cancer. It appears to provide valid information for first-degree relatives and common cancers** (Aitken, Bain, Ward, Siskind, & MacLennan, 1995; Kerber & Slattery, 1997; Ziogas & Anton-Culver, 2003), and **only slightly less accuracy for reports of second and third-degree relatives (Ziogas & Anton-Culver, 2003), and reproductive-tract cancers** (Kerber & Slattery, 1997). In general, this issue needs more research, but caution should be exercised when obtaining reports concerning non-first-degree relatives and/or more unusual, stigmatized, or less salient conditions.

Self-Reported Psychosocial Risk Factors among Cancer Patients

Secondary and tertiary prevention research often assesses and intervenes on

processes that affect the cancer experience. These include health-related quality of life and medical adherence and, **because there are often no reliable biomedical markers for these factors, self-report is the primary assessment method.**

Although we describe both quality of life and medical adherence in more detail below, self-report can be more generally improved by including collateral reports from spouses or family members and/or utilizing structured clinical interviews (rather than “paper and pencil” self-report).

Quality of life. It is well established that many cancer patients experience reduced quality of life (QoL), and that QoL has become an important outcome measure in cancer research. Reduced QoL can be identified through specific limitations in physical, role, cognitive, emotional, and social functioning. QoL decrements have been well documented among multiple populations, such as in breast (Roth, Lowery, Davis, & Wilkins, 2005) and colorectal cancer patients (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004), among many others. Researchers often create their own QoL self-report instruments, although several published measures are available (e.g., the SF-36; McHorney, Ware, Lu, & Sherbourne, 1994).

The **Functional Assessment of Cancer Therapy** (FACT-G; Cella et al., 1993; Fairclough & Cella, 1996) questionnaires are a validated set of general measures (n = 3), cancer specific measures (n = 18), cancer specific-symptom measures (n = 11), treatment specific measures (n = 4), and symptom specific measures (n = 12).

Evidence suggests that the FACT-G has smaller coefficients of variations and larger effect sizes compared to other commonly used tools (Cheung, Goh, Thumboo, Khoo, & Wee, 2005). In addition to patient self-reports of QoL, physician evaluations may be valuable. In particular, some evidence suggests that **physician reports are more**

sensitive in recognizing changes in patient physical or general health than are patient reports (Sneeuw et al., 1997). Caregiver reports may also be a complementary source of information, particularly when a patient report is judged to be less reliable (e.g., for social desirability reasons; Sneeuw et al., 1997).

Medical adherence. Most patients with cancer receive some form of treatment (oral, chemotherapy, or radiation) as part of their regimen. In these cases, medical adherence is essential to reduce morbidity and increase longevity. Multiple approaches are used to determine whether patients are taking their prescribed medication at the correct dosage and frequency (Atkins & Fallowfield, 2006), adhering to inpatient and outpatient treatments, and attending appointments. Treatment adherence can be assessed using both objective (e.g., drug levels in blood or urine) and subjective (e.g., diary, interview, or clinical interview self-report) methods.

Although evidence suggests that poor adherence is a barrier to effective treatment (Atkins & Fallowfield, 2006; Hoagland, Morrow, Bennett, & Carnrike, 1983; Miaskowski et al., 2001), **treatment adherence for cancers is generally higher than for other medical conditions** (e.g., diabetes, sleep disorders, pulmonary diseases; see DiMatteo, 2004; cf. Escalada & Griffiths, 2006). Factors related to non-adherence have also been studied. For example, among breast cancer patients, poorer adherence is related to more prescriptions at baseline (Lash, Fox, Westrup, Fink, & Silliman, 2006), treatment side effects or psychological distress (Demissie, Silliman, & Lash, 2001; Hoagland et al., 1983), low medication efficacy expectations (Fink, Gurwitz, Radowski, & Guadagnoli, & Silliman, 2004), positive node status (Demissie et al., 2001; Fink et al., 2004), better physical functioning (Demissie et al., 2001), and younger age (Partridge, Wang, Winer, & Avorn, 2003). **However, the extant studies**

of treatment adherence (particularly outside of medication regimens) have generally relied on self-reports, with little research examining the validity of patients' self-reported adherence to cancer treatment. A necessary first step appears to be the generation of standardized definitions and instruments for treatment adherence assessments in cancer patients (Escalada & Griffiths, 2006). In addition, researchers assessing medical compliance should include items that differentiate intentional (willful) versus non-intentional noncompliance (Atkins & Fallowfield, 2006).

In short, research among cancer populations includes multiple psychosocial factors that are measured using self-report. Evidence exists for the validity of existing tools to measure quality of life. Additional methods of assessing medical adherence are needed. We will see tremendous advancements as innovative methods are developed to measure these constructs.

Application of Self-Report Measures in Cancer

Limitations and biases associated with self-report in general. Despite the importance of self-reports, some important general limitations to the methodology do exist. **Participants are usually quite confident in their own ability to recall** (Fienberg, Loftus, & Tanur, 1985; Read, Vokey, & Hammersley, 1990), **yet a growing body of empirical evidence indicates that retrospective self-reports are susceptible to numerous errors.** Research in the field of autobiographical memory suggests that the magnitude of retrospective reporting errors is significant, and can threaten the validity of the information obtained (e.g., Jobe & Mingay, 1991). Autobiographical memory refers to both specific memory of personal episodes and generic knowledge about the self (e.g., Robinson & Swanson, 1990). When recalling self-relevant information, individuals may reproduce a particular incident relatively

directly (episodic memory), or reconstruct this information based on more generic views of the self (semantic memory).

The recall of information is also affected by many external factors, such as time since frequency, the event's last occurrence, and emotions associated with the event. Recent, *low* frequency, emotionally laden incidents are more easily retained (White, 1989) compared to other incidents that quickly fade and become hard to recall (Engle & Lumpkin, 1992). Thus, one's annual mammogram from last month would be more easily retained than one's exercise behavior the previous week. Memory about the source of the information (e.g., when and/or where the incident took place) is also often confused, because specific time and location indicators are lost as similar incidents get integrated into more generic knowledge (Means, Mingay, Nigam, & Zarrow, 1988).

Self-reports are also subject to a range of biases, such as poor memory or inability to accurately summarize past experiences (e.g., Engle & Lumpkin, 1992), current states (e.g., mood; Jobe & Mingay, 1991), **frequency of events** (Blair & Burton, 1987; Cummings, Nevitt, & Kidd, 1988; Smith, Jobe, & Mingay, 1991), and **temporal information** (Larsen & Thompson, 1995). In the development of cancer-related measures, it might be preferred to focus on assessments of more recent versus distant past events or experiences. Similarly, obtaining reports of current states rather than past states may be more accurate. When asking participants or patients about the frequency of events, experiences, or states (e.g., "*How often have you...?*"), researchers should consider providing appropriate recall cues, clearly delivering the questions, and structuring interviews to probe for confusion on the part of respondents. It is also desirable to emphasize to respondents the importance of

correct rather than normative responding, and to provide sufficient time and systematic strategies to rely on elaborative introspection rather than recall heuristics (that are more prone to bias).

Aside from cognitive errors arising from memory and recall strategies, there are motivational factors responsible for volitional misrepresentations.

Researchers and clinicians should consider that patients often want to present themselves in a favorable manner (a social desirability bias), and that this motivation might affect the validity of self-reports. **The effects of social desirability are especially pronounced when answering sensitive topics** (e.g., cancer patients who continue to smoke cigarettes, patients who are not taking their medications; e.g., Smith, 1992) or **when self-reports are obtained in a public** (as oppose to private and/or confidential) context (e.g., Rasinski, Baldwin, Willis & Jobe, 1994). Secondary gain is another source of volitional misrepresentations. **Secondary gain** refers to external and incidental advantages derived from behaviors and/or illness (e.g., rest, gifts, personal attention, release from responsibility, disability benefits). In short, those who can gain benefits by misrepresenting their state of affairs may willfully choose to do so. **Social stigma** is associated with severe social disapproval, and thus people may choose to avoid discussing behaviors or illnesses that are stigmatized out of fear that the information may be disclosed (Jones & Forrest, 1992). It is vital to provide and emphasize confidentiality, and to boost motivation, in order to obtain honest and open responses under these circumstances.

Suggestions for use of self-report for cancer-related variables.

Converging evidence indicates that researchers should not solely rely on self-report but rather supplement it with gold standard objective measures.

However, if self-reports are the only practical option, one should utilize strategies that we know will improve validity. In the past two decades, a multitude of attempts have been made to improve the accuracy of self-reports (Huber & Power, 1985; Loftus, Fienberg, & Tanur, 1985). In this section, we offer some practical considerations for using self-report methods for cancer-related variables. In selecting measures, one should explore the extant literature on the accuracy of self-report for the variables of interest, determine whether valid and reliable measures exist for the study population, and whether they are content valid for the assessed constructs. Researchers should also consider the use of **retrieval aids** (e.g., timeliness, landmarks; Loftus & Marburger, 1983; Smith, Jobe, & Mingay, 1991), **increased response time for participants** (Hammersley, 1994), **bounded-recall interviews** (Babor et al., 1990), and **motivational boosts** (Baker & Brandon, 1990). Finally, convergent evidence can be obtained from others (e.g., spouse, physician, caregiver) who have access to the domain of assessment.

Alternatives to retrospective self-reports (time based assessments)

Experience sampling methodology (ESM) & ecological momentary assessment (EMA). An alternative to dealing with the associated problems of retrospective self-reports is to reduce the interval of recalled assessments to more immediate or momentary judgments. In a typical ESM or EMA study, **participants are asked to carry a data entry device, such as a Palmtop computer, with a built in alarm that signals them to record their current location, activity, and feelings multiple times throughout the day.**

EMA can improve the accuracy of self-reports for several reasons (see also Smyth & Stone, 2003). First, it enables assessment in participant's naturalistic life

settings, which rules out the possibility that findings are an artifact unique to unnatural experimental settings. Second, the reports of EMA are momentary and not reconstructive. Third, depending on the nature of the research question, the timing of assessment can be random or event contingent. In addition to avoiding recall biases, EMA allows for detailed analysis of within-subject effects. EMA data are also suitable for examining complex diurnal cycles and interactions or between-effects of environmental and psychosocial factors.

EMA is not a perfect assessment method, however. Given the intense nature of the assessments, the response burden is higher than typical for both researchers and participants. Although a preliminary study has reported otherwise (Cruise, Broderick, Porter, Kaell, & Stone, 1996), **the possibility that intensive monitoring can affect daily experiences (i.e., reactivity) needs further scrutiny.** Special equipment and knowledge are required to develop and conduct the study, and analysis of the overwhelming number of multivariate data entries may seem initially overwhelming (see Schwartz & Stone, 1997). Furthermore, EMA is **appropriate for more frequently occurring events or experiences but is less well suited for collecting self-report information about uncommon events.** Also, given the technical and logistic requirements of its use, EMA is difficult and costly to implement for use in very large samples (e.g., National surveys).

Day reconstruction method (DRM). DRM combines a time-use study with a technique for recovering affective experiences (Kahneman, Krueger, Schkade, Schwarz, & Stone, 2004). **DRM asks participants to revive memories of the previous day by constructing a diary consisting of a sequence of episodes. They are then asked to describe each episode by answering questions about the**

situation and about the feelings that they experienced (comparable to the experience sampling method). This process provides an accurate picture of the experience associated with activities and circumstances. Evoking the context of the previous day is intended to elicit specific and recent memories, thereby reducing errors and biases of recall (Robinson & Clore, 2002). Although DRM is still being tested, **it has been shown to reproduce the information collected by ESM with less response burden and no disruption to daily activities.** Additionally, DRM also provides information about the duration of each experience.

Cancer researchers should consider these two approaches as ways to improve the accuracy of information gained from self-reports. EMA is ideal for the study of rapidly changing states and frequently occurring events, whereas DRM is more suited for studies of extremely rare events, when the duration of a particular event is in question, and/or studies involving very large numbers of respondents. Thus, in addition to continued development of assessment strategies, it is important to clarify which strategies would best serve to fit the focus and the emphasis of the study at hand.

Overall Conclusions

In sum, there are several mechanisms through which cancer researchers can attempt to maximize the utility of self-report data. These include using established instruments, assessing recent versus past events or states, providing cues to enhance recall, ensuring the clarity of all self-report questions, and including training to reduce (and probes to assess) confusion. Also, researchers should be aware of items that request information on potentially sensitive topics, and consider the impact of social desirability and stigma on findings. **Under ideal circumstances, a multi-method**

approach for convergent validity with self-report data should be used. Gold standard, objective, or other validation methods should be used whenever possible to corroborate patient self-reports (e.g., CO, cotinine, measured weight in light clothing, measured height without shoes, measured BMI, measured BP, measured fasting serum cholesterol, pathology test results, medical records). Researchers can also use alternative measures of self-report such as narrative data (e.g., Lane & Viney, 2005) or key informant reports (e.g., physician, family, or significant others). When self-report is the only option, multiple types of subjective reports ought to be included to increase the validity of findings. Finally, researchers should consistently describe their data collection methods and steps taken to maximize self-report accuracy, and indicate how the use of self-report measurements may limit conclusions.

References

- Aitken, J., Bain, C., Ward, M., Siskind, V., & MacLennan, R. (1995). How accurate is self-reported family history of colorectal cancer? *American Journal of Epidemiology*, *141*(9), 863-871.
- Arndt, V., Merx, H., Stegmaier, C., Ziegler, H., & Brenner, H. (2004). Quality of life in patients with colorectal cancer 1 year after diagnosis compared with the general population: A population-based study. *Journal of Clinical Oncology*, *22*(23), 4829-4836.
- Atkins, L., & Fallowfield, L. (2006). Intentional and non-intentional non-adherence to medication amongst breast cancer patients. *European Journal of Cancer*, *42*, 2271-2276.
- Baker, T.B., & Brandon, T.H. (1990). Validity of self-reports in basic research. *Behavioral Assessment*, *12*, 33-51.
- Babor, T.F., Brown, J., & Del Boca, F.K. (1990). Validity of self-reports in applied research on addictive behaviors: Fact or fiction? *Behavioral Assessment*, *12*, 5-32.
- Blair, E., & Burton, S. (1987). Processes used in the formulation of behavioral frequency reports in surveys. *Proceedings of the Section on Survey Methods Research: American Statistical Association*, 167-172.
- Bleiker, E.M., Menko, F.H., Taal, B.G., Kluijdt, I., Wever, L.D., Gerritsma, M.A., et al. (2005). Screening behavior of individuals at high risk for colorectal cancer. *Gastroenterology*, *128*(2), 280-287.
- Botvin, E.M., Botvin, G.J., Renick, N.L., Filazzola, A.D., & Allegrante, J.P. (1984). Adolescents' self-reports of tobacco, alcohol, and marijuana use: Examining the

comparability of video tape, cartoon and verbal bogus-pipeline procedures.

Psychological Reports, 55, 379-386.

Bowman, J.A., Redman, S., Dickinson, J.A., Gibberd, R., & Sanson-Fisher, R.W.

(1991). The accuracy of Pap smear utilization self-report: A methodological consideration in cervical screening research. *Health Services Research*, 26(1), 97-107.

Bowman, J.A., Sanson-Fisher, R., & Redman, S. (1997). The accuracy of self-reported Pap smear utilization. *Social Science and Medicine*, 44(7), 969-976.

Bradburn, N.M., Rips, L.J., & Shevell, S.K. (1987). Answering autobiographical questions: The impact of memory and inference on surveys. *Science*, 236, 157-161.

Campanelli, P.C., Dielman, T.E., & Shope, J.T. (1987). Validity of adolescents' self-reports of alcohol use and misuse using a bogus pipeline procedure. *Adolescence*, 22, 7-22.

Caplan, L.S., McQueen, D.V., Qualters, J.R., Leff, M., Garrett, C., Calonge, N. (2003). Validity of women's self-report of cancer screening test utilization in a managed care population. *Cancer Epidemiology, Biomarkers, and Prevention*, 12, 1182-1187.

Cargiulo, T. (2007). Understanding the health impact of alcohol dependence. *American Journal of Health-System Pharmacy*, 64(5), S5-S11.

Cavadini, C., Decarli, B., Dirren, H., Caudey, M., Narring, F., & Michaud, P.A. (1999). Assessment of adolescent food habits in Switzerland. *Appetite*, 32, 97-106.

Cella, D.F., Tulsky, D.S., Gray, G., Sarafian, B., Lloyd, S., Linn, E., et al. (1993). The Functional Assessment of Cancer Therapy (FACT) scale: Development and

- validation of the general measure. *Journal of Clinical Oncology*, 11(3), 570-579.
- Cheung, Y.B., Goh, C., Thumboo, J., Khoo, K.S., & Wee, J. (2005). Variability and sample size requirements of quality-of-life measures: A randomized study of three major questionnaires. *Journal of Clinical Oncology*, 23(22), 4936-4944.
- Cruise, C.E., Broderick, J., Porter, L., Kaell, A.T., & Stone, A.A. (1996). Reactive effects of diary self-assessment in chronic pain patients. *Pain*, 67, 253-258.
- Cohen, G., & Java, R. (1995). Memory for medical history: Accuracy of recall. *Applied Cognitive Psychology*, 9, 273-288.
- Cummings, S.R., Nevitt, M.C., & Kidd, S. (1988). Forgetting Falls: The limited accuracy of recall of falls in the elderly. *Journal of the American Geriatrics Society*, 36, 613-616.
- Demissie, S., Silliman, R.A., & Lash, T.L. (2001). Adjuvant tamoxifen: Predictors of use, side effects, and discontinuation in older women. *Journal of Clinical Oncology*, 19, 322-328.
- DiMatteo, M.R. (2004). Variations in patients' adherence to medical recommendations: A quantitative review of 50 years of research. *Medical Care*, 42(3), 200-209.
- Doll, R., & Peto, R. (1981). The causes of cancer: Quantitative estimates of available risks of cancer in the United States today. *Journal of the National Cancer Institute*, 66, 1191-1308.
- Engle, P.L. and Lumpkin, J.B., (1992). How accurate are time-use reports? Effects of cognitive enhancement and cultural differences on recall accuracy? *Applied Cognitive Psychology*, 6, 141-159.
- Escalada, P. & Griffiths, P. (2006). Do people with cancer comply with oral chemotherapy treatments? *British Journal of Community Nursing*, 11(12),

532-536.

- Fairclough, D.L., & Cella, D.F. (1996). Functional Assessment of Cancer Therapy (FACT-G): Non-response to individual questions. *Quality of Life Research, 5*, 321-329.
- Fendrich, M., Mackesy-Amiti, M.E., Johnson, T.P., Hubbell, A., & Wislar, J.S. (2005). Tobacco-reporting validity in an epidemiological drug-use survey. *Addictive Behaviors, 30*, 175-181.
- Field, A.E., Colditz, G.A., Fox, M.K., Byers, T., Serdula, M., Bosch, R.J., et al. (1998). Comparison of 4 questionnaires for assessment of fruit and vegetable intake. *American Journal of Public Health, 88*, 1216-1218.
- Fienberg, S.E., Loftus, E.F., & Tanur, J.M. (1985). Cognitive aspects of health survey methodology: An overview. *Milbank Memorial Fund Quarterly: Health and Society, 63*(3), 547–564.
- Fink, A., Gurwitz, J., Radowski, W., Guadagnoli, E., & Silliman, R. (2004). Patient beliefs and tamoxifen discontinuation in older women with estrogen receptor-positive breast cancer. *Journal of Clinical Oncology, 22*, 3309-3315.
- Fisher, M.A., Taylor, G.W., Shelton, B.J., & Debanne, S.M. (2007). Sociodemographic characteristics and diabetes predict invalid self-reported non-smoking in a population-based study of U.S. adults. *BioMed Central Public Health, 7*, 33.
- Frank, G.C., Nicklas, T.A., Webber, L.S., Major, C., Miller, J.F., & Berenson, G.S. (1992). A food frequency questionnaire for adolescents: Defining eating patterns. *Journal of the American Dietetics Association, 92*, 313–318.
- Gordon, N.P., Hiatt, R.A., & Lampert, D.I. (1993). Concordance of self-reported data and medical record audit for six cancer screening procedures. *Journal of the*

National Cancer Institute, 85(7), 566-570.

Grønbaek, M., & Heitmann, B.L. (1996). Validity of self-reported intakes of wine, beer, and spirits in population studies. *European Journal of Clinical Nutrition, 50(7), 487-490.*

Hacker, E.D., & Ferrans, C.E. (2007). Ecological momentary assessment of fatigue in patients receiving intensive cancer therapy. *Journal of Pain and Symptom Management, 33(3), 267-275.*

Haley, N., & Hoffman, D. (1985). Analysis for nicotine and cotinine in hair to determine cigarette smoking status. *Clinical Chemistry, 31, 1598-1600.*

Hall, H.I., Van Den Eeden, S.K., Tolsma, D.D., Rardin, K., Thompson, T., Sinclair, A.H., et al. (2004). Testing for prostate and colorectal cancer: comparison of self-report and medical record audit. *Preventive Medicine, 39, 27-35.*

Hammersley, R. (1994). A digest of memory phenomena for addiction research. *Addiction, 89 (3), 283-294.*

Hataway, J., & Bragg, C. (1984). Cancer: What is prevention? *Family & Community Health, 7 (1), 59-71.*

Hiatt, R.A., Perez-Stable, E.J., Quesenberry, Jr., C., Sabogal, F., Otero-Sabogal, R., & McPhee, S.J. (1995). Agreement between self-reported early cancer detection practices and medical audits among Hispanic and non-Hispanic white health plan members in North Carolina. *Preventive Medicine, 24, 278-285.*

Hoagland, A.C., Morrow, G.R., Bennett, J.M., Carnrike, Jr., C.L. (1983). Oncologists' views of cancer patient noncompliance. *American Journal of Clinical Oncology, 6(2), 239-244.*

Huber, G.P., & Power, D.J. (1985). Retrospective reports of strategic level managers:

- Guidelines for increasing accuracy. *Strategic Management Journal*, 6, 171-180.
- Hughes, J.R., Keely, J.P., Niaura, R.S., Ossip-Klein, D.J., Richmond, R.L., & Swan, G.E. (2003). Measures of abstinence in clinical trials: Issues and recommendations. *Nicotine and Tobacco Research*, 5, 13-25.
- Huttenlocher, J., Hedges, L.V., & Bradburn, N.M. (1990). Reports of elapsed time: Bounding and rounding processes in estimation. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 16(2), 196-213.
- Issacs, S.D., Kiemeny, L.A., Baffoe-Bonnie, A., Beaty, T.H., & Walsh, P.C. (1995). Risk of cancer in relatives of prostate cancer probands. *Journal of the National Cancer Institute*, 87, 991-996.
- Janz, K.F., Golden, J.C., Hansen, J.R., & Mahoney, L.T. (1992). Heart rate monitoring of physical activity in children and adolescents: The Muscatine study. *Pediatrics*, 89, 256–261.
- Jobe, J.B., & Mingay, D.J. (1991). Cognition and survey measurement: History and overview. *Applied cognitive Psychology*, 5, 172-192.
- Jones, E.E., & Sigall, H. (1971). The bogus pipeline: A new paradigm for measuring affect and attitude. *Psychological Bulletin*, 76, 349-364.
- Jones, E.F., & Forrest, J.D. (1992). Underreporting of abortion in surveys of U. S. Women: 1976 to 1988. *Demography*, 29, 113-126.
- Jordan, T.R., Price, J.H., King, K.A., Masyk, T., Bedell, A.W. (1999). The validity of male patients' self-reports regarding prostate cancer screening. *Preventive Medicine*, 28, 297-303.
- Kahneman, D., Krueger, A.B., Schkade, D., Schwarz, N., & Stone, A.A. (2004). A survey method for characterizing daily life experience: The Day Reconstruction

- Method (DRM). *Science*, 306(3), 1776-1780.
- Kentala, J., Utriainen, P., Pahkala, K., & Mattila, K. (2004). Verification of adolescent self-reported smoking. *Addictive Behaviors*, 29, 405-411.
- Kerber, R.A., & Slattery, M.L. (1997). Comparison of self-reported and database-linked family history of cancer data in a case-control study. *American Journal of Epidemiology*, 146(3), 244-248.
- Key, T. J., Allen, N. E., Spencer, E. A., & Travis, R. C. (2002). The effect of diet on risk of cancer. *The Lancet*, 360, 861-868.
- Kohl, H.W., Fulton, J.E., & Caspersen, C.J. (2000). Assessment of physical activity among children and adolescents: A review and synthesis. *Preventive Medicine*, 31, S54-S76.
- Lane, L.G., & Viney, L.L. (2005). The effects of personal construct group therapy on breast cancer survivors. *Journal of Clinical and Consulting Psychology*, 73, 284-292.
- Larsen, S.F., & Thompson, C.P. (1995). Reconstructive memory in the dating of personal and public news events. *Memory and Cognition*, 23(6), 780-790.
- Lash, T.L., Matthew, P.F., Westrup, J.L., Fink, A.K., & Silliman, R.A. (2006). Adherence to tamoxifen over the five-year course. *Breast Cancer Research and Treatment*, 99, 215-220.
- Livingstone, M.B.E., Prentice, A.M., Coward, W.A., Strain, J.J., Black, A.E., Davies, P.S.W., et al. (1992). Validation of estimates of energy intake by weighed dietary record and diet history in children and adolescents. *American Journal of Clinical Nutrition*, 56, 29-35.
- Loftus, E.F., Fienberg, S.E., & Tanur, J.M. (1985). Cognitive psychology meets the

- national survey. *American Psychologist*, 40(2), 175-180.
- Loftus, E.F., & Marburger, W. (1983). Since the eruption of Mt. St. Helens, has anyone beaten you up? Improving the accuracy of retrospective reports wit landmark events. *Memory and Cognition*, 11(2), 114-120.
- Luepker, R., Pallonen, U., Murray, D., & Pirie, P. (1989). Validity of telephone surveys in assessing cigarette smoking in young adults. *American Journal of Public Health*, 79, 202-204.
- Lykins, E.L., Pavlik, E.L., & Andrykowski, M.A. (2007). Validity of self-reports of return for routine repeat screening in an ovarian cancer screening program. *Cancer Epidemiology, Biomarkers, and Prevention*, 16(3), 490-493.
- Masi, C.M., Blackman, D.J., & Peek, M.E. (2007). Interventions to enhance breast cancer screening, diagnosis, and treatment among racial and ethnic minority women. *Medical Care Research and Review*, 64, 195S-242S.
- McGovern, P.G., Lurie, N., Margolis, K.L., & Slater, J.S. (1998). Accuracy of self-report of mammography and Pap smear in a low-income urban population. *American Journal of Preventive Medicine*, 14(3), 201-208.
- McHorney, C.A., Ware, Jr., J.E., Lu, J.F., & Sherbourne, C.D. (1994). The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care*, 32(1), 40-66.
- McPhee, S.J., Nguyen, T.T., Shema, S.J., Nguyen, B., Somkin, C., Vo, P., et al. (2002). Validation of recall of breast and cervical cancer screening by women in an ethnically diverse population. *Preventive Medicine*, 35, 463-473.
- Means, B., Mingay, D.J., Nigam, A. & Zarrow, M. (1988). A cognitive approach to

enhancing health survey reports of medical visits. In M.M. Gruneberg, P.E. Morris & R.N. Sykes (Eds.), *Practical aspects of memory: current research and issues* (pp. 537-542). Chichester: John Wiley & Sons.

Miaskowski, C., Dodd, M.J., West, C., Paul, S.M., Tripathy, D., Koo, P., et al. (2001).

Lack of adherence with the analgesic regimen: A significant barrier to effective cancer pain management. *Journal of Clinical Oncology*, 19(23), 4275-4279.

Murray, D., O'Connell, C., Schmid, L., & Perry, C. (1987). The validity of smoking self-reports by adolescents: A re-examination of the bogus pipeline procedure. *Addictive Behaviors*, 12, 7-15.

Newell, S.A., Girgis, A., Sanson-Fisher, R., & Savolainen, N.J. (1999). The accuracy of self-reported health behaviors and risk factors relating to cancer and cardiovascular disease in the general population: A critical review. *American Journal of Preventive Medicine*, 17(3), 211-229.

Paiva, I., Amaral, T., & Barros, H. (2004). Influence of individually estimated portion size on the assessment of nutritional risk in colorectal cancer in Portugal. *Journal of Human Nutrition and Dietetics*, 17(6), 529-536.

Palta, M., Prineas, R.J., Berman, R., & Hannan, P. (1982). Comparison of self-reported and measured height and weight. *American Journal of Epidemiology*, 115, 223-230.

Partridge, A., Wang, P., Winer, E., Avorn, J. (2003). Nonadherence to adjuvant tamoxifen therapy in women with primary breast cancer. *Journal of Clinical Oncology*, 21, 602-606.

Patrick, D., Cheadle, A., Thompson, D. C., Diehr, P., Koepsell, T., & Kinne, S. (1994). The validity of self-reported smoking: A review and meta-analysis. *American*

Journal of Public Health, 84, 1086-1093.

- Rasinski, K.A., Baldwin, A.K., Willis, G.B., & Jobe, J.B. (1994). Risk and loss perceptions associated with survey reporting of sensitive behaviors. In *Proceedings of the Section on Survey Research Methods of the American Statistical Association* (pp. 497-502). Washington, DC: The American Statistical Association.
- Read, J.D., Vokey, J.R., & Hammersley, R. (1990). Changing photos of faces: Effects of exposure duration and photo similarity on recognition and the accuracy-confidence relationship. *Journal of Experimental Psychology: Learning, Memory and Cognition, 16, 870–882.*
- Richardson, M.T., Leon, A.S., Jacobs, D.R., Jr., Ainsworth, B.E., & Serfass, R. (1995). Ability of Caltrac accelerometer to assess daily physical activity levels. *Journal of Cardiopulmonary Rehabilitation, 15, 107–113.*
- Robinson M.D., & Clore, G.L. (2002). Belief and feeling: Evidence for an accessibility model of emotional self-report. *Psychological Bulletin, 128, 934-960.*
- Robinson, J.A., & Swanson, K.L. (1990). Autobiographical memory: The next phase. *Applied Cognitive Psychology, 4, 321–335.*
- Rockett, H.R.H., Breitenbach, M., Frazier, A.L., Witschi, J., Wolf, A.M., Field, A.E., et al. (1997). Validation of a youth/adolescent food frequency questionnaire. *Preventive Medicine, 26, 808–816.*
- Roth, R.S., Lowery, J.C., Davis, J., & Wilkins, E.G. (2005). Quality of life and affective distress in women seeking immediate versus delayed breast reconstruction after mastectomy for breast cancer. *Plastic and Reconstructive Surgery, 116(4), 993-1002.*

- Russell, T., Crawford, M., & Woodby, L. (2004). Measurements for active cigarette smoke exposure in prevalence and cessation studies: Why simply asking pregnant women isn't enough. *Nicotine and Tobacco Research, 6*(2), S141-151.
- Sallis, J.F., Buono, M.J., Roby, J.J., Micale, F.G., & Nelson, J.A. (1993) Seven-day recall and other physical activity self-reports in children and adolescents. *Medicine and Science in Sport and Exercise, 25*, 99-108.
- Sallis, J.F., & Saelens, B.E. (2000). Assessment of Physical Activity by Self-Report: Status, Limitation and Future Directions. *Research Quarterly for Exercise and Sports, 71* (2), S1–S14.
- Schoeller, D.A. (1995). Limitations in the assessment of dietary energy intake by self-report. *Metabolism , 44*, 18–22.
- Schofield, P.E., & Hill, D.J. (1999). How accurate is in-patient smoking status data collected by hospital admissions staff. *Aust NZ J Public Health, 23*, 654-656.
- Schwartz, J.E., & Stone, A.A. (1997). Data analysis for EMA studies. *Health Psychology, 17*, 6-16.
- Shopland, D.R., Eyre, H.J., & Pechacek, T.F. (1991). Smoking-attributable cancer mortality in 1991: Is lung cancer now the leading cause of death among smokers in the United States? *Journal of the National Cancer Institute, 83*, 1142-1148.
- Smith, A.F., Jobe, J.B., & Mingay, D.J. (1991). Questions induced cognitive biases in reports of dietary intake in college men and women. *Health Psychology, 10*(4), 244-257.
- Smith, T.W. (1992). A methodological analysis of the sexual behavior questions on the

- General Social Surveys. *Journal of Official Statistics*, 8(3), 309-325.
- Smyth, J., & Stone, A. (2003). Ecological momentary assessment research in behavioral medicine. *Journal of Happiness Studies*, 4, 35-52.
- Sneeuw, K.C., Aaronson, N.K., Sprangers, M.A., Detmar, S.B., Wever, L.D., & Schornagel, J.H. (1997). Value of caregiver ratings in evaluating the quality of life of patients with cancer. *Journal of Clinical Oncology*, 15(3), 1206-1217.
- Stone, A.A., Shiffman, S.S., & DeVries, M. (1999). Rethinking our self-report assessment methodologies: An argument for collecting ecological valid, momentary measurements. In Kahneman, D., Diener, E., & Schwarz, N. (Eds.). *Wellbeing: The foundations of hedonic psychology*. (pp. 26-39). New York: Russell Sage Foundation.
- Thompson, C.P., Skowronski, J.J., & Lee, D.J. (1988). Telescoping in dating naturally occurring events. *Memory and Cognition*, 16, 461-468.
- Trentham-Dietz, A., Nichols, H.B., Hampton, J.M., & Newcomb, P.A. (2006). Weight change and risk of endometrial cancer. *International Journal of Epidemiology*, 35, 151-158.
- Trock, B., Lanza, E., & Greenwald, P. (1990). Dietary fiber, vegetables, and colon cancer: Critical review and meta-analysis of the epidemiologic evidence. *Journal of the National Cancer Institute*, 82, 650-661.
- U. S. Department of Health and Human Services. (1988). *The surgeon general's report on nutrition and health*. Washington, DC: Department of Health and Human Services, Public Health Service, 88-50210.
- Vacek, P.M., Mickey, R.M., & Worden, J.K. (1997). Reliability of self-reported breast screening information in a survey of lower income women. *Preventive Medicine*,

26, 287-291.

Verreault, R., Brisson, J., Deschenes, L. & Naud, F. (1989). Body weight and prognostic indicators in breast cancer: Modifying effect of estrogen receptors.

American Journal of Epidemiology, 129, 260-268.

Weaver, T.W., Kushi, L.H., McGovern, P.G., Potter, J.D., Rich, S.S., King, R.A., et al.

(1996). Validation study of self-reported measures of fat distribution. *International Journal of Obesity*, 20, 644-650.

White, R.T. (1989). Recall of autobiographical events. *Applied Cognitive Psychology*, 3, 127-136.

Wills, T.A., & Cleary, S.D. (1997). The validity of self-reports of smoking: Analyses by race/ethnicity in a school sample of urban adolescents. *American Journal of*

Public Health, 87(1), 56-61.

Ziogas, A., & Anton-Culver, H. (2003). Validation of family history data in cancer family registries. *American Journal of Preventive Medicine*, 24(2), 190-198.

Zulkifli, S.N., & Yu, S.M. (1992). The food frequency method for dietary assessment.

Journal of American Diet Associations, 92, 681-685.