Social Work in Health Care

Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/wshc20

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Published online: 08 Oct 2008.

To cite this article: Betsy Vourlekis PhD & Kathleen Ell DSW, PhD (2007): Best Practice Case Management for Improved Medical Adherence, Social Work in Health Care, 44:3, 161-177

To link to this article: http://dx.doi.org/10.1300/J010v44n03_03

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Best Practice Case Management for Improved Medical Adherence

Betsy Vourlekis, PhD
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SUMMARY. Less than optimal treatment adherence for many health conditions impedes clinical progress, leading to increased morbidity, mortality and health care costs, particularly for low-income and racial and ethnic minority patients. When properly understood as a complex phenomenon involving patient, provider, and health system interacting factors, adherence improvement is a natural target for social work’s multi-system model of case management. We present five key elements for a generic “best practice” case management blueprint applicable to a range of medical settings. The theory and evidence base for the elements are discussed and illustrated with SAFe, a tested social work case management program to improve adherence following abnormal cancer screens. doi:10.1300/J010v44n03_03 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2007 by The Haworth Press, Inc. All rights reserved.]
Optimal health improvement strategies for many diseases and health problems often require longer-term adherence to recommended regimens, including medication compliance, regular periodic screening, diet control, and follow-up on referrals. Yet the World Health Organization estimates that even in developed countries only 50% of patients adhere to treatment recommendations (WHO, 2003). Inadequate and non-existent health care resources are an important contributing factor, but many other barriers influence patient adherence thereby impacting on clinical progress and, ultimately, morbidity, mortality and health care costs. Low-income racial and ethnic minority persons are particularly at high risk for poorer health outcomes (Institute of Medicine, 2003).

Treatment adherence is a complex phenomenon resulting from the interplay of a number of potential barriers operating in the patient, provider and wider health care system. Patient blaming is a common response of health care professionals that overlooks the intricate field of influences on patient behavior. Experts recognize that successful approaches to improved adherence across a range of diseases must accurately assess barriers on a case by case basis and target multiple systems with more than one intervention (WHO, 2003). Properly understood, the problem of non or less than optimal adherence is a natural target for social work’s multi-system spanning model of case management with its comprehensive focus. Linked to the important outcome of medical adherence, social work case management for carefully targeted high-risk populations is an important value-added component to health care.

Increasingly, case management approaches are being developed and tested to promote preventive, diagnostic and treatment follow-up adherence for a range of medical conditions including asthma, cancer, HIV/AIDS, coronary disease, diabetes, and depression (Evans et al., 1999; Freeman et al., 1995; Gilbody et al., 2003; Hunkeler et al., 2000; Karter et al., 2004; Laramee et al., 2003; Lipkus et al., 2000; Magnus et al., 2001; Malta et al., 2003; Philis-Tsimikas and Walker, 2000; Pugh et al., 2001; Riegel et al., 2002; Webber and Reilly, 1997.) However, existing approaches to case management are highly variable and may address some barriers such as patient education or system snafus, but not both and ignore others. Although professional standards (NASW, 1992) exist and CDC has promulgated guidelines for AIDS
and breast and cervical screening programs (CDC, 1999), these are general statements of process rather than specified intervention models with evidence-based components. In addition to the imprecision and variability surrounding implementation of case management, cost concerns and limited reimbursement for case management also constrain administrators’ views.

Consequently a viable social work case management model for today’s health care environment will need to offer a comprehensive evidence-based and cost-sensitive approach. In this paper we present a suggested generic “best practice” case management approach to improve adherence for medical conditions, and illustrate its key components in a specific case management program. The approach is based on (1) a conceptual and theoretical framework for understanding barriers to optimal health care; (2) links between the framework and specific case management components and activities; and (3) evidence supporting the utility and effectiveness of the key case management components.

**THE PROBLEM OF ADHERENCE**

Effective case management requires a comprehensive understanding of the problem of non-adherence. The World Health Organization’s recent inclusive review of adherence research in nine chronic disease conditions sets forth a five-dimensional explanatory model and summarizes factors found to be significant for each dimension (WHO, 2003). Adherence is affected by the interaction among social and economic factors, particularly minority status and poverty, health system and health care provider-team factors, condition/illness-related factors, therapy or treatment-related factors, and patient-related factors such as level of knowledge, health beliefs and attitudes, and hopelessness (WHO, 2003). To this model we would add the overarching influence of cultural factors, operating at patient, health care provider, and larger health system levels to shape perceptions, attitudes, communications, and resource allocation in ways that impede optimal adherence outcomes.

**Barriers to Adherence**

Research documents this complex set of person-environment factors and interactions that contribute to medical non-adherence (e.g., Clark, 2003; Jacobson et al., 1990; Johnson et al., 2003; see WHO, 2003 for a
comprehensive treatment of this research). Individual barriers include lack of knowledge, health beliefs and attitudes, limited problem-solving skills, depression and other mental disorders, including substance abuse. Social and economic barriers can be absence of social support, pressing economic and family distractions, and a lack of practical resources such as transportation and childcare. There are multiple potential barriers in the health system and clinical care process, including inadequate or inaccessible resources, poor communication, lengthy waits, lost or incomplete records, and poorly organized and coordinated delivery systems. Also contributing to non-adherence are health condition factors specific to the particular illness or health problem such as degree of disability, symptom severity, and the presence of co-existing disorders, as well as therapy or treatment related factors such as side-effects and complexity and duration of the regimen (WHO, 2003). Cultural influences potentially operate on any of the above factors. Many efforts to improve patient adherence address just one or two potential barriers or fail to identify individual differences in circumstances, with disappointing results.

**Theory-Driven Intervention**

The strength of social work case management is its ecologically valid multiple interacting systems (life-space) intervention field. However, the case manager needs a better-specified blueprint for specific intervention strategies within this complex field of influencing factors. We formulate a theoretically derived model of health actions and decisions that incorporates the multiple factors influencing adherence and links them to key case management strategies. The model combines elements from the Health Belief Model (Becker, 1974), Transtheoretical Model (Prochaska & DiClemente, 1994), and Socio-cultural Explanatory Theory (Ashing-Giwa, 1999). Health behavior and outcomes are viewed as the result of a decisional-interaction process (involving the patient with a specific illness/condition, the provider, the recommended treatment/therapy regimen, and the health care system) that includes predisposing (knowledge, attitudes, coping skills, resources), reinforcing (social support, cues to action, adequate communication), and enabling (resource acquisition, reduction of practical obstacles, system responsiveness) influences in the “health condition” life space.

Regardless of the illness or disease, case management to improve adherence consists of capability to provide bundles of activities/techniques designed to affect predisposing, reinforcing and enabling influences on a patient’s behavior that are to be used differentially on a case by case basis,
depending on individualized comprehensive assessment. For example, case management includes interventions aimed at enhancing a patient’s self-management skills—such as a self-prompt system—practice in forming and asking questions of the provider, exploration and education concerning perceptions and understanding of the health problem and the resources available to cope with the health threat, and clinical counseling to reduce psychological distress. All of these possible activities target predisposing influences. Another set of potential activities strengthens reinforcing influences; for example, facilitating communication of information between health care workers and patient, providing reminders through supportive reinforcing informational messages, or intervention with family and other network members. A third set of activities addresses enabling influences and includes patient referral for psycho-social resources, assistance in problem-solving with competing priority difficulties, assistance with clinic and care process obstacles and complexities, and locating and establishing linkages to needed resources for the entire clinic. Recognition of the cultural influences operating is critical in all three areas. For example, culturally derived perceptions of the meaning of illness and its treatment are an important component of patient “understanding” which “education” alone will not necessarily influence. Likewise, indifference or rudeness in a clinic setting may interact with a patient’s culturally derived suspiciousness or skepticism about the provider system. Culturally mediated beliefs, practices and preferences of patients, their families, and the providers of the health care system may contribute to a variety of poor “fits” in the health care decisional process. Figure 1 illustrates the relationships among case management activities, adherence barriers and patient outcomes based on concepts of the health decision model.

A CASE MANAGEMENT BLUEPRINT

Research on adherence and the theoretically driven intervention model outlined above suggest there are five essential features of a case management intervention blueprint to improve medical adherence. An effective approach must (1) be integrated carefully into the clinical medical care process; (2) be culturally competent; (3) be individualized and interpersonal; (4) intervene in multiple systems; and (5) provide feedback to the care system for quality improvement. Each element is discussed below and illustrated from SAFe, a specific social work case management program designed to improve patient adherence to diagnostic follow-up following abnormal breast and cervical cancer screens.
**SAFe Case Management**

SAFe (Screening Adherence Follow-up) was developed and tested over a five-year period in multiple sites with a target population of medically underserved, minority women at higher risk of non-adherence (Ell, Vourlekis, Muderspach et al., 2002; Ell, Padgett, Vourlekis et al.,...
SAFe aims to improve women’s adherence, empower women to increase health competence over the long run, provide culturally responsive services, enhance clinic access to community resources, and improve continuity and efficiency of care.

SAFe is interpersonal time-limited case management provided by a case manager (BSW or human-service trained/experienced) and clinical social worker (MSW) team. SAFe combined strategies of proven efficacy into a comprehensive approach, providing patient education and supportive emotional counseling (Lerman, Hanjani, Caputo et al., 1992), systems navigation (Freeman, Muth, & Kerner, 1995), “bridging” help between patients and providers, as well as customary case management activities of resource acquisition, monitoring care, and patient advocacy. The case manager provides most of the service; the clinical social worker sees a small percentage of women with mental disorders and/or severe psychosocial circumstances and supervises the case manager. Women receive services at the appropriate level for a period of six months to one year or until recommended diagnostic follow-up is completed or until entry into treatment.

SAFe improved patient adherence significantly over site baseline rates, non-enrollee rates, and control group rates, with rates of adherence improving from 6% to 25%. In the SAFe randomized control trial, women receiving SAFe case management achieved equal or higher rates of both adherence and timely adherence across all severity classification categories for both mammography and PAP when compared to women in the control group. Adherence rates were similar across ethnic groups, and improvements achieved across urban and rural community based screening clinics, urban diagnostic and treatment medical centers, and geographic regions (Ell, Vourlekis, & Padgett, 2003).

**FIVE KEY ELEMENTS FOR EFFECTIVE CASE MANAGEMENT**

**Integration of Services**

Effective case management requires a designated case manager(s) that is carefully integrated into the health care setting and its routine clinical processes. Focused on both patient and health care system/provider barriers, case managers must have timely access to charts, schedules and patients and be readily accessible to clinical staff. Since case management activities are tied to reducing adherence barriers, they are
coordinated with the actual timing and procedures of clinical care processes to the greatest degree possible.

In SAFe, while all low-income women with abnormal screens were eligible for case management, there were substantial difficulties locating and reaching women after they had been informed of their results. Further integration of case management (and the case manager) with the clinical care processes so that case management initial assessment and intervention occurred along with notifying a woman of her results would have improved efficiency and decreased the problem of failure to locate women. For cost-efficiency, case management needs to be a targeted service (based on known risk populations) and/or provided only after assessment reveals probable barriers or a trigger event, such as a missed appointment, occurs. Whatever the approach, service criteria and screening processes need to be transparent to all clinic staff and integrated with existing medical appointment routines to the maximum.

**Cultural Competence**

Effective case management requires trained culturally competent case managers (Brach and Fraser, 2000). Recruiting bi-lingual and/or bi-cultural case managers and clinicians for the population served may be a high priority. In addition, case managers need training to understand and respect the multiple influences of cultural beliefs, practices, and preferences on the health care decisional process and to recognize where specific advocacy may be required for equal access to resources.

SAFe recruited personnel in keeping with site demographics. Overall the SAFe clientele to date has been 72% Hispanic, 10% African American, 6% White, 5% Chinese (accounting for most of the clientele at one site) and the remaining 7% “other.” Only 25% of patients were American born. All of SAFe’s materials were translated into Spanish and Chinese, and services were offered in these languages if a woman preferred. Initial case manager training included extensive discussion of cultural beliefs and practices with respect to cancer and health care, systematic identification of the social contextual realities of different minority groups served by the clinics (e.g., illegal aliens in California; length of time in the country; family structures and expectations). Ethnically targeted resources were identified to the extent possible (i.e., cancer information in Spanish; Spanish-speaking hot line). On-going supervision and discussion of culturally mediated attitudes and behaviors was provided. For example, as evidence accumulated linking almost all cervical cancer to the sexually transmitted virus HPV, case managers had to augment their edu-
cational interventions to include both explanations and explorations of sexual practices and beliefs within a cultural framework.

**Individualized Services**

Case management should be individualized, interactive and patient-centered, addressing the specific health circumstances of the patient and only the barriers and needs actually identified. It is not a “one size fits all” intervention. Systematic comprehensive assessment of each patient (covering the range of known potential barriers to adherence) should guide a case management plan and activities in accord with general service protocols for different levels of service intensity. Not all patients need the same type of help or the same amount of help. Cost-conscious case management needs to make differential use of personnel depending on patient need and focus on immediate barriers to adherence. Interaction may be face-to-face or on the telephone.

SAFe developed an initial scripted assessment and intervention that is provided to all women eligible for case management. Embedded in the script (which takes 20-30 minutes) are evidence-based questions about the range of potential barriers to adherence together with queries and educational responses specific to the woman’s own circumstances. For example, if the woman is scheduled for a needle biopsy, she is asked if she understands what this is and then provided with a simple explanation. Educational messages about abnormalities versus having cancer are reinforced several times. When women identify barriers such as transportation and childcare, case managers first ask women if they have or can now think of possible solutions. Mental health screening is done with a standard instrument, the Patient Health Questionnaire, a version of PRIME-MD (Spitzer et al., 1999). Using a woman’s responses to all of the assessment questions, the case manager generates a risk profile and the woman is assigned to one of three levels of service using a clinical decision-making algorithm derived from the evidence about risks contributing to non-adherence. Thus the care plan is directly generated from the initial contact.

To date SAFe has served 1,331 women across all study sites. Slightly less than half (45%) received minimal assistance from the case manager (initial assessment plus educational supportive counseling and a reminder call later), 36% Level II (Level I plus systems navigation and/or resource referrals) and 19% level III (Level I or II plus MSW short-term clinical intervention). Data from SAFe shows that women assigned to different service levels actually do receive progressively more contacts as needs
intensify, and that adherence rates are equally good for women regardless of level of service (Vourlekis, Ell, & Padgett, 2005). Women’s circumstances sometimes change during the period of case management service, necessitating a reassignment of service level as additional service is indicated.

**Multi-System Interventions**

Case management protocols and service plans should be designed to address any potential contributing factor to the adherence problem, based on systematic consideration of predisposing, reinforcing, and enabling influences on patient behavior. Considering first the patient-system, specific interventions aim to reduce patient predisposing factors. These interventions include patient-tailored information/education, emotional support to reduce psychological distress, empowerment strategies to increase patient competence in problem solving and health self-management, and exploration of perceptions about availability of adequate resources to cope with the demands of the health threat.

Routine interventions aimed at enhancing reinforcing factors should consider a range of systems such as mobilizing greater social support, patient reminders about appointments and requirements through supportive reinforcing informational messages, and facilitating communication (“bridging intervention”) between a patient and health care provider to improve mutual understanding thereby reinforcing medical directives.

Enabling interventions should target barriers in the wider social system such as lack of transportation or child care, clinic scheduling that interferes with a patient’s work, uncoordinated care, or developing linkages to needed resources such as low-cost or free medications, mental health/substance abuse care, translation services and legal assistance. Empowerment strategies should involve the patient in problem solving to the extent possible to increase self-care competency.

SAFe’s scripted initial assessment and intervention assures that all potential adherence-influencing factors are examined to begin with and provides specific educational information concerning a woman’s specific health circumstances. Data from SAFe shows the most frequently identified barrier is that a woman does not understand the screening result and/or the recommended follow up (predisposing factor). Thus educational counseling and emotional support are provided to all women in this initial contact.
Separate scripts for the initial case management contact were written for mammography and gynecology patients. Use of scripted health education information is important for case managers who, while trained in the content of the health information, are not specialized health educators. It is critical that the health information be specific to the woman’s circumstances, stated simply, and absolutely accurate. The script, while time consuming to develop initially, provided consistency and clarity in the educational message.

To illustrate, a woman with an abnormal PAP smear would hear the following sequence of information: “Do you know what a PAP test is for?” After the woman answers (even if somewhat correctly) the case manager says “(That’s right) A PAP test or PAP smear is a simple, painless test used to find female cancers of the cervix or uterus. The cervix is the lower narrow end of the uterus or womb (The womb is where the baby develops). A few cells are removed from the cervix and studied under the microscope to see if there are any abnormal changes in the cells.” Following some additional questions about whether the woman has been asked to have a follow-up exam and in the event she has the case manager says “There are different reasons that women may have for not being able to keep scheduled appointments or to follow other recommendations. I’m going to name some of these and I’d like you to tell me if each one may be true for you.” The woman is then asked about her understanding of what she is to come back for. She is then asked about her understanding of the different possible follow-up exams. After she answers, and, as above, even if partly correct, the case manager provides the following information: “If results of your PAP smear showed that you need another exam, then it is necessary to do a more complete exam of your cervix. One possible exam is to repeat the PAP smear. Another exam is a colposcopy, which is like a regular female exam, except the doctor uses a magnifying device to look at your cervix. A colposcopy can find problems, like abnormal changes in cells in your cervix at a very early stage, before there is a chance for you to get cervical cancer. If there is a problem, early treatment can completely prevent cancer of the cervix.”

Farther along in the interview the case manager probes about fear of cancer as follows: “Some women say that they are afraid that if they have the exam, they might find out they have a serious problem. Do you have any worries like this?” If the woman indicates yes the case manager replies, “A PAP test result that requires you to have a further exam usually does not mean you have cancer. In fact, very few of the follow-up exams show cancer. Most show abnormal cells in the cervix that
will later become cancer if they are not treated. But if you find and treat the problem early, you can completely prevent cancer of the cervix. The best way to find the problem early is to get this follow-up exam. Even if the exam does show cancer, there is an excellent chance of a total cure, if it’s found early enough. If you do go for your follow-up exam, and find out that there is not a serious problem, then you’ll be able to stop worrying. Even if there is a problem, in almost all cases, it can be easily cured.”

The case manager asks specifically about a woman’s previous experiences with the clinic and its personnel. Perhaps a woman reports that her health providers do not answer her questions satisfactorily. When her expectations are negative and her sense of self-efficacy to deal with difficulties low, the case manager uses empowerment techniques such as validating the importance of her concerns, suggesting practice in writing the questions down ahead of time, and even coaching and rehearsing how to ask. The case manager will educate at any point of contact to dispel a woman’s mistaken ideas about her medical condition or the treatments needed. For example, a woman who is clinically depressed but believes “that is just the way life is” is helped to understand that this is a medical condition that can be treated and she can feel better. She is offered a choice of referral for medication or brief “talking” therapy with the MSW and in some instances will choose or is encouraged to use both.

SAFe recognizes the importance in many cultures of a family view of health and illness, as well as the belief in the primacy of the family unit rather than the individual. Therefore addressing the reinforcement influence of family members may be needed. Women with cervical abnormalities particularly fear negative family reactions to diagnosis and treatment. Helping women voice their fears, re-framing their situation (“your family needs you; will they be better off if you become truly ill and incapacitated, whatever the cause?”), and, in some cases, speaking/meeting directly with family members to enlist help and support are a part of case management. Finding ways to improve patient-provider communication and understanding enhances trust and openness, which in turn shape and reinforce medical directives. Locating and/or providing translation services is frequently needed, and developing a resource base for sporadic translation service to a multi-ethnic clientele is challenging.

SAFe case managers work in overburdened, understaffed and under funded clinical settings with absolute resource shortages. Digging up usable resources and then working with patients to access them requires
dedication to creative problem solving. Since in most cases enabling factors rest in the environment, not the patient (although effort and persistence is required of the patient), it is here that many models and practitioners of case management fall down. This can result in overly focusing on predisposing factors in the patient and, when problems remain, blaming the patient. Or the case manager becomes discouraged and defeatist, identifying with the powerlessness of the client. SAFe uses peer consultation and discussion with other colleagues to identify, develop and link with resources and to strategize best access tactics for over-loaded services. In general, medical and nursing colleagues understand that there are formidable resource difficulties and are deeply respectful and appreciative of SAFe case managers’ tenacious efforts. Supervisory and administrative clinic staff constantly reinforce and acknowledge the importance of and skill required in dealing with environmental barriers.

**Quality Improvement**

There is a continual tension in case management between the case-specific focus of the work and the frequent reality of broken, ill-designed care processes and systematic service delivery problems that cut across many or all patients. Individual case managers cannot be expected to solve larger system failures and inadequacies that may contribute to problems in adherence. However, a case management program is a quality improvement addition to a health care setting when straightforward processes to monitor its information and activities are built in, providing useful information to managers about system and resource problems.

SAFe uses two case management process quality indicators—(1) timely identification and contact with eligible women and (2) identification of health system barriers—to examine case manager service records routinely for systemic problems that are then brought to the attention of administrators and policy-makers who have responsibility for improvement. This does not guarantee improvement will occur, but data and visibility concerning problems is often a strong motivator for change. For example, as SAFe began in one large urban medical center the case managers found that many women they called, who had abnormal results noted in their charts, had not, in fact, been informed of this. SAFe protocol required the case manager to discontinue the interview and to inform the clinic of the non-notification, resulting in problems with timely contact. After investigating, it was learned that the notification process consisted of a single part-time clerk. Another person had left many months before and
the position had not been filled. The flaw in the clinic process was a serious one, and bringing it to light resulted in a rapid response and improvement. Another case management program, similar to SAFe, includes monitoring of provider adherence to the clinic’s own standard of care guidelines as it tracks patient adherence to prescribed procedures and appointments. It is not the case manager’s responsibility to interfere with medical provider practices, but data from the case management program provides to administrators quality improvement information on provider behavior (Engelstad et al., 2002; Engelstad et al., 2001).

CONCLUSION

The model of case management discussed and illustrated here is a complex practice modality appropriate for a carefully targeted population of patients known to be at high risk for non-adherence. For settings serving a high risk population, the outlined five key elements of effective case management can be adapted to a variety of diseases and health conditions and the clinical settings that address them. Although the general categories of adherence barriers are similar across health problem and patient populations, careful analysis of the condition-specific research base concerning known adherence barriers will lead to modification or augmentation of the assessment tool and identification of the specific differences in the presentation of factors. For example, medication compliance for persons with HIV makes substantial organizational demands on a patient, whereas medication compliance for persons with schizophrenia may be influenced more by the patient’s concern about stigma. Appropriately scripted health information salient to the specific health problem and range of likely treatment/therapy possibilities would need to be written. And the most effective and feasible approaches to successful integration of case management with existing clinical processes would vary by setting.

The SAFe model of case management brings a critically necessary social work perspective to the problem of adherence. Widely recognized as a problem involving both patients and systems, adherence improvement requires the ability to fully understand and address difficulties in system-patient interactions and to craft interventions that can target either or both. When successfully targeted only to those who are at higher risk, and provided only to the degree dictated by a patient’s unique circumstances, social work case management is an affordable and uniquely multi-system intervention.
NOTE

To learn more about SAFe and for adaptable resources to support case management for improved adherence, a fully specified tool kit for SAFe Case Management, including the Service Manual, Training Manual, scripts, and data collection instruments is available online at www.usc.edu/dept/socialwork/research/safe/

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doi:10.1300/J010v44n03_03