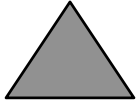


Breaking the Silence: Violence/Abuse Issues for Women Diagnosed with Serious Mental Illness:



INTRODUCTION

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" This is the powerful connection between women's experiences with physical and sexual abuse and the health and mental health damage left in its wake. It is a given that this damage is uniquely disabling, easily confounded by diagnoses of serious mental illness and shrouded in the mists of stigma."

Salasin, 1995)

(Susan

Over the last two decades, women have organized against the violence that shapes their lives. However, women diagnosed with serious mental illness who have been victimized, especially women of color, have remained an invisible group of under-served and inappropriately served women. Women diagnosed with serious mental illness are assaulted in families, on the street, and sometimes in the psychiatric institutions that are supposed to protect them (Carmen, 1995).

Work by a number of researchers and clinicians over the past decade has documented the extent of trauma and abuse experiences in the lives of women diagnosed with mental illness, and the link between chronic abuse and the development of psychiatric disorders. Studies have shown

that up to 72 percent of psychiatric inpatients have histories of physical or sexual abuse or both (Carmen et al., 1984; Mills et al., 1984; Rieker and Carmen, 1986; Bryer et al., 1987; Jacobsen & Richardson, 1987; Craine et al., 1988; Carmen and Rieker, 1989.) Women diagnosed with serious mental illness tend to have experienced multiple abuses and trauma. Because the report of abuse, if given at all, is often decontextualized it is viewed by providers as unbelievable or unrecognizable.

Carmen and Rieker, (1986, 1989, 1995), have given one of the clearest and most relevant descriptions of the decontextualization of abuse:

[Often the] "...victim's 'adjustment' occurs by altering the reality of the victimization so that both the abuse experience and the victim's thoughts, feelings and behaviors become congruent with family and society norms and expectations; namely: it didn't happen; it happened but it wasn't important and has no consequences; the victim provoked (and deserved) it; it wasn't abusive. The common features of the process through which victims accommodate to others include a) denying the abuse, b) altering the affective responses to abuse and c) changing the meaning of abuse."

(Carmen, 1995a, pgs. 47-48).

Silence, self-blame and forgetting are part of the accommodation process through which victims "adjust" to pressures to "forget" and minimize the abuse. Thus, in order to survive many women have been silenced. This paper is written to break this silence. It reflects the

collective voices of consumers/ survivors/ ex-patients
(c/s/x) and providers.

" Despite the large numbers of victims/survivors found in psychiatric settings, mental health professionals remain generally unaware of the social and psychological consequences of abuse. There is still considerable confusion and resistance within psychiatry about the relevance and meaning of abuse for understanding and treating psychiatric disorders. Without adequate training, clinicians are less likely to ask about abuse experiences as part of client evaluations or to consider abuse related diagnoses, such as post-traumatic stress disorder and dissociative disorder. Consequently, victims are misdiagnosed or inadequately diagnosed."

(Carmen,
1995a, pg. 53)

The effect is to render the women invisible.

Women who have to struggle with severe mental illness or substance abuse problems or physical disabilities (that may be secondary to incidents of abuse) are even more vulnerable to abuse, yet face forms of discrimination that further decrease their likelihood of being taken seriously and/or of finding programs willing to accommodate them. There is an urgent need to develop new treatment strategies designed for victims of violence with severe psychological disabilities; these new treatment strategies mean a shift " from a traditional treatment approach to an advocacy-based model that acknowledges the broad social framework in which

abuse is perpetuated and treatment takes place" (Carmen, 1995; Warshaw, 1995).

Women diagnosed with serious mental illness are not a homogeneous group; there are important differences in culture and ethnicity, diagnosis, age, intellectual and functional capacity, abuse experiences, treatment histories, and life circumstances (Carmen 1995b). Cultural differences in gender socialization affect women's perceptions of abuse, their ability to access services, and their expectations of family and community support (Warshaw, 1995).

Crenshaw (1991) explored the various ways in which race and gender intersect in shaping structural, political, and representational aspects of violence against women of color. Where systems of race, gender, and class domination converge, as they do in the experiences of battered women of color, intervention strategies must acknowledge and effect solutions to combat different obstacles faced by women of color. Such is the case for immigrant women of color who are wholly dependent on their husbands (economically and linguistically, etc.) and may suffer abuse under threats of deportation by their husbands. Intersectional subordination need not be intentionally produced; in fact, it is frequently the imposition of one burden that interacts with pre-existing vulnerabilities to create yet another dimension of disempowerment. Women of color are differently situated in the economic, social, and political worlds. When reform

efforts undertaken on behalf of women neglect this fact, women of color are less likely to have their needs met than women who are racially and economically privileged.

- **Barriers**

▶ *Limits of the practice models.* When survivors of abuse seek treatment, they often have what Gelinas (1983) calls a "disguised presentation." Providers who are not adequately trained in sensitive interviewing for abuse may focus only on the many symptoms presented.

Warshaw (1989, 1995) has clearly reported that the medical model "is designed to extract information from the context of the patient's life that gives it meaning to her and transform it into medical events that have meaning for the clinician. It reduces information to categories that can readily be handled and controlled, transforms symptoms into disorders that can be treated or managed, and dismisses anything that does not fit the diagnoses or treatments that are known and available to that particular clinician or specialty." Neurochemistry or DSM-IV symptom lists sometime become more important to the provider than the woman sitting in front of her/him.

In a psychodynamic model or framework, a clinician may not play an active role in advocating for safety and helping the women to access community resources, including obtaining restraint orders and visiting battered women shelters. In a

substance abuse/recovery model, seeing the substance as the primary issue to be changed, when the use of alcohol or other drugs may have been an important survival skill allowing the women to remain passive and do what her violent partner wanted her to do, can be dangerous. Not understanding the complexities of the connections between substance abuse and violence against women may lead to escalating the violence.

▶ ***Lack of collaboration.*** Another barrier is the lack of the collaboration across all these systems -- health, mental health, substance abuse, and trauma services. For women with multiple vulnerabilities, particularly women diagnosed with serious mental illness who have been and/or are currently in abusive situations, and who use alcohol and other drugs, and may have a number of health problems, it is an overwhelming burden to navigate fragmented and competing systems. When a drug treatment program will not take a woman who self-injures, when a battered women shelter will not admit a woman who uses a drug, when a mental health program will not admit a woman diagnosed with serious mental illness with her children, when a medical provider speaks disrespectfully to a pregnant woman because of her substance abuse or doesn't listen to a woman (c/s/x) attempting to discuss her abuse history because she "is crazy", then our systems and programs are doing harm. Women who stay away from such programs are judging correctly. But even the most

sensitive programs/systems of care are not doing all they can for women with multiple vulnerabilities.

▶ **Reimbursement systems.** Warshaw (1995) also points out that a diagnosis-driven reimbursement system poses yet another set of problems. In order for a woman to access services, she needs a diagnosis; however, for a battered woman, just having a diagnosis may create a new danger. Psychiatric diagnoses are often used by batterers to "prove" that the partner's problems are "her fault," that she is "crazy," or that she is an unfit mother. Thus, in seeking treatment, she risks losing her children in custody battles and losing her validity in court. In addition, if she is insured on her husband's policy and the bills are sent to him, she may be placed in further jeopardy if he finds out she is seeking outside help.

If a woman is immobilized by depression or panic attacks, treatment is clearly warranted to help her be able to function and make choices that will ultimately lead her to safety. However, reframing these "disorders" as understandable responses to terror and entrapment leads us to a different set of intervention strategies and helps us keep our focus on the real dangers she faces. Providers need to work collaboratively with community groups of advocates and survivors to pool our resources and develop new ways of intervening on social as well as individual levels.

- **Safety Needs to be the First Concern**

Safety is the primary issue. Unless safety is addressed and addressed as soon as possible, another major barrier to effective intervention is present. We need to ask a woman diagnosed with serious mental illness about her current level of danger, what she thinks will help her be safe, what she has tried before and its effectiveness, and we need to discuss options and develop a safety plan with her. Becoming knowledgeable about state laws, the process of obtaining an order of protection, and the availability and quality of resources and shelters are also important. ***However, it is also important that we understand that some of the resources -- some hospitals, some homeless shelters-- are not safe for women.***

Part of shifting to an "advocacy" role means that providers need to no longer see themselves as the experts on a woman's choices of treatment. In a mental health system the treater is the expert, whereas in an advocacy system the survivors are the experts, which is central to the concepts of recovery and empowerment. Creating a healing environment means providing the "psychological safety for women to be able to fully know what they have experienced, to regain perspective, to feel the pain, the anger, the sadness, the grief and loss, as well as their strengths, and new possibilities, to reclaim the power they

have lost and the sense of being valued" (Warshaw, 1995). For women who do have disruptive or painful psychiatric symptoms, framing them in the context that contributed to them, helping to demystify and destigmatize their experience, discussing options, and encouraging choices are essential. Medications can be offered adjunctively as long as the woman participates in discussing their pros, cons, and possible impact (i.e., a true informed consent process), and it is made clear that she will not be defined by or controlled by her use of them.

• **Revictimization**

Failure to recognize, understand, and respond appropriately to a survivor's symptomatology may result in services that do not meet the needs of the client and may result in the woman's retraumatization or revictimization (e.g. consequences of the use of bed restraints.) For all clients, and especially women with a history of trauma, assessment processes are needed to include the client in (1) identifying specific circumstances that elicit potentially harmful behavior, and (2) understanding what responses can help the client de-escalate and feel safe (Carmen, et al, 1996). While training is important, shifting the orientation of staff members toward a recipient perspective about the quality and type of services rendered in psychiatric hospitals is equally needed.

Ann Jennings (1995), in her address at the Dare To Vision Conference, shared the experiences that many consumer/survivors have found in psychiatric institutions.

" Just as her childhood abuser had tied her up and held her down and bound her arms and hands, she was, in the system, repeatedly subjected to take-downs, restraints, and the shackling of her arms and legs to a bed. As her abuser had stripped her when she was a child, pulling her T-shirt over her head, she was, in the system, forcibly stripped of her clothing when secluded or restrained, often by or in the presence of male attendants. As her childhood abuser pulled off her pants leaving her with 'nothing on below,' so, in the system, her underpants were pulled down, often by male attendants, in order to forcibly inject her with medication. As the abuser had blindfolded her with her little T-shirt, towels or sheets were often thrown over her face if she spat or screamed while tied down with four-point restraints in mental hospitals. As her childhood abuser had opened her legs, so also, in four-point restraints, her legs were forced open and tied down in spread-eagle position. As her childhood abuser had examined and 'put things into her that hurt her,' so also institutional staff continually and painfully injected medication into her body against her will."

(Jennings, 1995, pg. 17)

In a recent study (Ray, Myers, Rapport, 1996) of 1,040 individuals who had been treated in New York State Psychiatric facilities, approximately half of the respondents reported that they had been subjected to restraint and seclusion. The vast majority of the respondents who had been restrained or secluded viewed the experience negatively. The most common complaint was that

the use of these interventions was premature, not necessary, and/or primitive. Analysis showed that respondents who had been restrained or secluded were twice as likely as other respondents to have given a very negative overall assessment of their inpatient care. Although almost all respondents who had been restrained or secluded had at least one complaint about the experience, ***those who believed that staff had made some express efforts to deal with their behavior or distress in a less restrictive way felt significantly less negative about the experience.***

Ridgeley (1997) has provided an excellent review of the effects of coercion on women in mental health treatment. A number of writers and consumers/survivor/ex-patients have described the devastating effects of coercive treatments, including involuntary commitment, restraint and seclusion; the effects included feelings of dehumanization, submissiveness, mistrust, invalidation of experience, revictimization, terror. (Deegan, 1995; Jennings, 1997).

Survivors have stated that forcing any intervention on unwilling clients risks creating an environment in which a controlling adult forces the woman to do something that she knows she doesn't want to do, replicating the dynamics of the trauma itself.

Stefan (1994) has written, " To be physically held down, to have one's body invaded by those who tell you that it is good for you, that they mean well for you, must have

particularly frightening -- even terrorizing -- meaning for the women with a history of sexual abuse." The Department of Mental Health in Massachusetts established a Task Force concerned with restraint and seclusion of persons who have been physically and sexually abused. Chaired by Dr. Elaine Carmen and made up of clinicians, consumers and advocates experienced in this area, the Task Force developed clinical guidelines on restraint/seclusion. While the guidelines initially were recommended for clients with a history of trauma, they have now been broadened to apply to all clients. Two Assessments Forms were developed: a Trauma Assessment Form and a De-Escalation Assessment Form. Both forms are written so that they may be completed either by the client or by staff. (See Appendix for Clinical Guidelines and Forms).

IMPLICATIONS FOR PRACTICE AND POLICY

Women with a diagnosis of serious mental illness who have been abused may have difficulty navigating separate systems of mental health, physical health, and victim services. Rather than continuing to place the entire burden on the woman, the systems need to develop linkages that integrate care and provide sensitive services.

This must be done with recognition that providers treating women diagnosed with a serious mental illness, particularly in the public sector, are often overburdened and understaffed. Linkage itself is not a panacea,

particularly when resources are severely limited. While integration of health, mental health, substance abuse and trauma services may be the ultimate goal, models of linkages and collaboration/ coordination will be important steps toward integration. By **integration** we mean that the women diagnosed with serious mental illness would be able to receive all needed services within a single service setting. **By linkage and/or collaboration/coordination** models we mean that all needed services are linked through some mechanisms such as case management or a coordinated system design.

However the linkages or integration are accomplished, what appears to be a key concept is that we can no longer do "business as usual." In order to meet the needs of women with multiple vulnerabilities, there need to be significant and real changes in our practices and policies.

• **Changing Practices**

Among the elements needed to improve services for women diagnosed with a serious mental illness and who have been victimized are the following:

▶ **Enhancing assessments: comprehensive assessment of physical health, mental health, trauma history and substance abuse.** At all entry points into the care system, there is need for a screening in these areas, followed by a more comprehensive assessment. A detailed history of trauma needs to be completed; physical abuse, sexual abuse, and

witnessing of abuse in childhood, adolescence, and adulthood need to be explored as completely and as sensitively as possible. If a woman has a trauma history, only minimal screening may need to be completed, until she feels ready and safe enough to allow a complete assessment, which should include physical screening, psychosocial assessment, and history of substance abuse, and trauma history. In addition, HIV counseling and risk reduction, with recommendations for testing when appropriate should be done. As part of the assessment, the woman should be asked to complete the De-Escalation Form mentioned earlier (See Appendix). All of these components should lead to a more sensitive and appropriate care plan developed in collaboration with the woman.

With women who have suffered a recent acute trauma, diagnosis may be fairly straightforward. However, for the women who have suffered prolonged, repeated trauma, disguised presentations are common. Explicit and sensitive questioning is required to determine whether the woman is presently living in fear of someone's violence or has lived in fear at some time in the past. Arriving at a clear diagnosis is most difficult in cases of severe dissociative disorder (Herman, 1992).

The first task of the assessment (and subsequent interventions) is to establish the survivor's safety (Herman, 1992; TIPS, 1997). Assessment needs to include the degree of structure necessary to ensure safety. Outpatient

care may be insufficient for a woman whose self-care is badly compromised; day treatment or residential care may be needed.

▶ ***Outreach to bring sensitive and respectful services to women diagnosed with a serious mental illness and trauma history.*** Mental health treatment sites need to ensure that there is a connection either on-site or through referral and follow-up to services for women who have been victimized. Other service providers, such as substance abuse treatment and trauma service providers, also need to ensure effective coordination for women diagnosed with serious mental illness. Particular attention also needs to be made to following-up with women after discharge from an institution. Consumers who are trained in outreach strategies and peer-support may be the most effective in reaching women.

▶ ***Educational Campaign.*** In order to truly reach women and enhance access to services, there needs to be a culturally competent, education campaign ("Partnership for Mentally Healthy Communities"). The campaign needs to include videotape and multi-media messages, and needs to explain in culturally appropriate and culturally competent ways what services are available and what entitlements are available. As part of an overall campaign, SAMHSA could target a year -1999- for Women, Violence and Mental Health.

Victims of violence who seek help often feel intimidated, shamed, stigmatized, retraumatized and silenced. Because individual and community support is so important to recovery and/or healing, community education about violence against women is critical. Better education -- of women, the health care community, and society in general--is essential. Consumers and providers also need education about managed care and managed care contracts.

► ***Staffing/Connections.*** The core experiences of psychological trauma are disempowerment and disconnection from others. Recovery, therefore, is based upon the empowerment of the woman and the creation of new connections. (Herman, 1992).

One of the ways in which providers can diminish the survivor's feelings of helplessness and increase a sense of empowerment is by increasing her range of choice. Consumer/survivor/ex-patients have shared over and over again that "what helped" them were caring, supportive and safe relationships, and that most often these relationships were not found in traditional health, mental health and substance abuse treatment institutions. In fact, often some of the most caring people were "on the streets" doing outreach and/or in more non-traditional settings.

In a similar vein, Schorr (1997) has written: "Case managers find that families known to an alphabet soup of agencies remain unhelped until someone finally is there long

enough and is close enough and persevering enough to forge the kind of authentic relationship that helps to turn lives around" (pg. 11).

For women, relationships are at the core of their lives and their decision making; i.e., a woman often will put her needs after the needs of her partner, her children, and her parents. It is important that providers understand that they need: to receive enhanced training regarding issues of violence and women diagnosed with serious mental illness; to redesign treatment/recovery programs within the context of women's lives; to understand the importance of the use of peer supports for the women; and to hire a number of consumer/survivor/ex-patients as staff.

► ***Training for Service Providers.*** Writing protocols and telling providers to ask about abuse does not work. Persuading clinicians that routine inquiry, assessment and intervention about abuse constitutes the current standard of care and then helping them to develop the skills and comfort needed to integrate this into routine practice is a slow and laborious process. Understanding the obstacles faced by both clinicians and women seeking care is essential to integrating recognition and intervention into standard clinical practice. The primary care sector needs better understanding regarding mental health problems and trauma, and the mental health/addictive services sector must do a better job of recognizing the consequences of trauma.

Providers need to learn specialized and client-sensitive interviewing techniques to assess impact of emotional problems on revealing health care problems, particularly when trauma, mental illness, and substance abuse can be confounding factors. Mental health professionals also need to recognize and take responsibility for the trauma experiences of their patients, either by making treatment of those problems part of the services they offer or ensuring that connections and follow-up are in place for their patients. Consumers/survivors/ex-patients should be an integral part of designing the training curriculum and co-facilitating the trainings.

Trainings need to include: sensitive interviewing techniques, assessment of prior and current trauma, practice guidelines, partnerships with consumers, issues of delayed stress; resources for women. Practice guidelines, similar to the restraint/seclusion guidelines, need to be developed for diagnoses/assessment. There is also the need for certification that appropriate training has occurred; providers should demonstrate competency to work with women with trauma histories.

While a number of efforts have been made to introduce domestic violence training into medical schools (ACOG, 1989; AMA, 1992), most of the training for primary care, mental health, and substance abuse providers has not focused on the issues of violence and trauma for women diagnosed with serious mental illness. Practitioners need training in

understanding women with multiple needs, problems, and vulnerabilities -- while also understanding and eliciting women's strengths and assets.

• **Training and Practice Guidelines**

From a policy perspective, it is necessary to explore options to move these elements forward. These policies could include:

▶ ***Developing criteria for state block grants regarding linkage among mental health, substance abuse, victim services, and primary care programs.*** These criteria should be accompanied by practice guidelines regarding best practices for women diagnosed with a serious mental illness, women with histories of physical and sexual abuse, and women with multiple vulnerabilities. The practice guidelines need to include the recent work on Seclusion and Restraint by the Massachusetts Task Force. (See Appendix).

▶ ***Practice guidelines need to differentiate between populations of trauma survivors:*** (1) Women who experienced abuse in childhood, adolescence, and/or adulthood; (2) Women who experienced abuse and serious mental illness; (3) Women who have histories of abuse, serious mental illness and substance abuse.

▶ *The issue of failure to recognize trauma symptoms in the face of mental disorders was noted earlier.* This failure may not just reflect a lack of clinical skills, but provider bias. A provider's knowledge of a diagnosis of past or present mental illness may lead the provider to be more dismissive of trauma symptoms. Alternatively, signs and symptoms of trauma/victimization can be "overinterpreted" as pathological or mental illness rather than a consequence of trauma. Training needs to include sufficient time on attitudes and skills building, as well as knowledge building. Specialized internships could be an additional training component.

▶ *The issues of culture, as well as the intersection of race and gender in shaping responses to violence and victimization experiences, need to be integral components in all training curricula and practice guidelines.* In addition, issues for lesbian women need to be addressed in the training.

▶ *Legal Issues.* Given the increasing numbers of women who face loss of children and other violations of civil/human rights as a result of stigma/discrimination associated with psychiatric labeling and past and/or present abuse, training providers and C/S/X regarding the protection of these rights, as well as available legal resources, is essential.

▶ ***Graduate Education.*** Graduate education at all levels needs to adopt an interdisciplinary approach to care that relates to biological, social, psychological, and spiritual needs of women. Educators, researchers, and practitioners should re-examine curricula, research agendas, and competencies with regard to the health/mental health of women. The knowledge base must be broadened to include an appreciation of basic biological differences between the genders, as well as the demographic, psychosocial, economic, and environmental factors that affect women's health/mental health.

Additional Practice Issues

▶ ***All intrusive strategies including seclusion, restraint, and forced medication should be considered as treatment failures on the part of the provider.*** There should be careful monitoring that other more "calming" and or de-escalation techniques have been explored completely with the woman.

▶ ***There needs to be acceptance and legitimization of alternative treatments, including acupuncture, home visits (for suicidality and other crises), etc.***

▶ *Best practices of peer support models need to be disseminated to providers.*

▶ *There needs to be recognition that consumer/survivor/ex-patient interests may not be the same as those of family members.*

▶ *There is need for additional research on medications and women.* This is important to ensure women's safety, as well as investigating the issue that newer drugs may be safer but more expensive (and therefore not reimbursed under cost containment system.)

• Evaluation and Outcomes

▶ *New models for conducting evaluations of programs to meet the needs of women diagnosed with serious mental illness also need to be developed.* In all evaluations and outcome studies, consumers/survivors/ex-patients should play an integral role in developing study designs, designing evaluation measures, assisting in training providers in utilizing evaluation measures, interpreting data, and disseminating results. For all evaluations, data privacy should be guaranteed. Legal and financial penalties for

confidentiality violations should be part of continuous surveillance.

- **Reimbursement/Incentive Design**

We are at a crisis point in health, mental health and substance abuse treatment. Crisis is both a danger and an opportunity. This should not be another "missed opportunity". The danger is that women and women and children will be harmed by cost containment designs and welfare reform. The opportunity is that we utilize the dismantling of traditional services to put in place a more effective, more sensitive, and "caring" system. This means that we change practices, we change providers, we change environments, and we change policies. In order to truly have an effective system of care, particularly for women with multiple vulnerabilities, we need to not ignore effective interventions and/or dilute them by cutting costs inappropriately. In addition, we need to look at the "real costs" in a long-term perspective -- and not for just four year blocks of time.

► *It is important to ensure that public reimbursement (Medicare, Medicaid) is of a sufficient level to cover the extensive outpatient services (in-depth assessment, preventive care, case management, medications, transportation, child care) needed, as well as the*

additional time needed for women diagnosed with serious mental illness and trauma history.

▶ ***Reimbursement mechanisms that promote continuity (e.g., managed care) should be monitored to ensure that they provide access to medical, mental health and victim services specialists.*** There needs to be recognition of the potential for times of crisis in the lives of women diagnosed with a serious mental illness and of the fact that gatekeeping functions may exacerbate these crises.

▶ ***As much as possible, hospitalizations should be voluntary and with the control of the consumer/survivor/ex-patient.*** An advance agreement specifying the circumstances requiring treatment, medications, or hospitalization can be quite helpful. Involuntary treatment should be considered as a systems failure. If a woman is involuntarily committed, there should be a penalty to the provider. There should be incentives to keep women out of hospitals, unless hospitalization is absolutely necessary; "Necessity" should be judged by a Consumer Protection Committee, including a significant number of Consumer Representatives. However, it should also be noted that, sometimes it is also difficult, under present cost containment, to admit a woman into the hospital when she requests it.

▶ **Oversight.** In all managed care contracts, there should be an Oversight Committee and an outside appeals process. Consumer/survivor/ex-patient representatives should be part of these processes.

▶ ***Changes in health care delivery systems may impair efforts to deliver effective treatments and create more integrated community care facilities for women.*** Innovative programs serving women with co-occurring mental illness and substance abuse and histories of violence and abuse may lose funding under the push toward cost-containment. States should guarantee that these innovative programs are funded.

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