Meeting Challenges of Late Life Disability Proactively

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Abstract

Discussions of disability in the gerontological and the disability studies literatures have seldom considered unique perspectives and needs of older adults. Disability has often been stigmatized and viewed as antithetical to successful aging. We call for expansion of prevailing paradigms of disability to address the resilience and continuing human potential of older adults living with disabilities. In addition to recognizing the environmental context of disability, we propose greater attention to adaptive potential of disabled older adults. We discuss 6 types of proactive adaptations that can contribute to empowerment, meaning, enhanced quality of life and psychological well-being among persons living with late-life onset disabilities. These include: (a) helping others, (b) planning for future care, (c) marshaling intergenerational support, (d) self-advocacy for responsive health care, (e) making environmental modifications to improve safety and comfort of the home, and (f) finding strength in spiritual pursuits. Enacting proactive adaptations can contribute to resilience in facing late life impairments and functional limitations. Such efforts can complement utilization of services and obtaining accommodations. Maintaining life satisfaction among older adults living with disabilities also involves focus on transcendent personal goals and acceptance of an altered self. We note how a more integrative view of medical and social dimensions of disability, infused with concepts of human agency, contributes to rapprochement between alternative disciplinary orientations to late life disability. Without negating society’s important responsibilities for accommodating to needs of older adults living with disability, we reaffirm their potential for greater control and self-determination through proactive adaptations.

Keywords: Disability, Disability models, Environmental modifications, Helping, Intergenerational support, Planning, Proactive adaptations, Self-advocacy, Spirituality

Translational Significance This article calls for recognizing and encouraging personal efforts by older adults who develop disabilities in late life to build on their strengths and engage in active coping efforts to live fulfilling lives. Service providers and policy planners can best contribute to these efforts by making services available that support self-determination and respect unique adaptations of older adults with disabilities.

If one were to ask older persons what they fear the most, surely the loss of their health and developing disability would rank high on the list. Having lived well thus far without disability, the idea of entering the world of impairment toward the end of their lives can be a scary and unpredictable place. Many older people particularly fear the
prospects of being a burden to others. This essay ventures into the world of late life disability and aims to dispel some of the fears associated with developing a disability in later life. Specifically, we hope to distill lessons learned from exploring the intersection of aging and disability undertaken in our recent book Disability and Aging: Learning from Both to Empower the Lives of Older Adults (Kahana & Kahana, 2017). We offer further reflections, building on the authors’ multidisciplinary perspectives (sociology, history, and psychology) to elucidate factors that can foster resilience among older adults who are aging into disability. Disability for older adults is not the result of failure (or the lack of “successful aging”), nor should it be attended with shame or stigma. Indeed, disability can provide new opportunities to find greater meaning in life. We see both disability and aging as mutually supporting concepts both for the individual living into old age with disability and for the respective fields of disability studies and gerontology. In this article, we seek to address unique challenges and opportunities in exploring disability in the context of old age. We focus on adaptive skills that can contribute to well-being among older adults living with disabilities.

Disablement has been defined as the impact of acute and chronic conditions on people’s abilities to act in necessary, usual and expected ways in their society (Verbrugge & Jette, 1994). It is well recognized that rates of disablement increase greatly in very old age, with the vast majority of elders over age 85 being unable to perform all activities of daily living independently (Freedman, Martin, & Schoeni, 2002). There are consistent findings that disability prevalence is higher among women. This trend, combined with greater longevity of older women, “results in older women spending more years living in a disabled state” (Fried & Guralnick, 1997, p. 92). Mobility limitations are the most prevalent late life disabilities with 18% of those over age 85 reporting such limitations (Simpson, 2005). In addition to visible and readily identifiable disabilities, many older adults suffer from chronic illnesses that result in extreme fatigue or other invisible disabilities (Welch, 2016).

Expanding Existing Disability Paradigms to Fit Unique Needs of Older Adults

Currently, there are two major models that serve as frameworks for understanding disability: the social model is espoused by disability studies scholars and the medical model is adopted in much of gerontological research. The social model considers disability to be a reflection of society’s inattention to human needs and invokes societal responsibilities for making accommodations to create suitable environmental supports for the disabled. It is primarily focused on young persons and places disability into an interpersonal and policy context (Shakespeare & Watson, 2002). In contrast, the medical model is focused on definitions and assessment of disability as being based on physical impairments and functional limitations of the individual (Verbrugge & Jette, 1994). It calls for rehabilitation in a medical context as a way to compensate for disabilities. The social model is concerned with victimization of the disabled and demands to offer societal solutions that ensure their participation in social roles. In considering factors that can facilitate well-being among older adults living with disabilities we draw on both of these models of disability (Kahana & Kahana, 2017). We also add a focus on individual, personal adaptations including proactive adaptations (Kahana & Kahana, 2003).

There have been numerous recent critiques in the literature of the dominant disability models (Haegle & Hodge, 2016; Kavanagh, 2018; Owens, 2015) and several alternative models have been proposed. Additional paradigms have been advanced in the context of economics, framed as the capabilities approach (Mitra, 2006; Sen, 2002) and from an international perspective, highlighting functioning and environmental opportunities (Altman, 2001). Notably none of these models are specifically focused on late life disability. Helpful reviews of disability models in relation to aging with long term disabilities have been offered by Putnam (2002). She emphasizes the importance of person–environment transactions for defining disability and calls attention to neglect of research on persons with life-long disabilities, who are now attaining old age (Putnam, 2017). She also calls for crossing network lines in service provision to disabled persons who are attaining old age.

We believe that scholars of aging have the potential to refine the understanding and conceptualization of disability as a sociological and historical concept and pay attention to the value of both psychological and social adaptations, thereby contributing greatly to a renewed and expansive understanding of disability. This can also help theorize aging in more complex ways—and permit room for empirical studies and theoretical frameworks in gerontology to grow and evolve in discussion with disability scholars, and with health scholars.

We argue that it is important to bring about dialogue between scholars of disability studies and scholars of aging. Each of these fields has valuable insights. Disability studies better reveals how social and environmental factors can be as disabling as impairments of the mind and body. They envision disability as a liberating concept that empowers people, notwithstanding the challenges they face (Oliver, 1995). The Americans with Disabilities Act of 1990 (ADA), achieved through social activism, prohibits discrimination on the basis of disability and provides critical accommodations to those with disabilities. This may be viewed as a triumph of the disability studies movement (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Nevertheless, older adults are not likely to be involved in work or school environments, where accommodations are most prevalent (DeLeire, 2000). In this essay, we discuss how the social model can be expanded to consider individual efforts to cope with disability (Baltes & Baltes, 1990). We recognize that the medical model correctly
addresses the etiology and measurement of disability and recognizes the stressful aspects of disability. However, it is limited in consideration of human agency in adapting to disability. Learning to live with disability in late life is a multifaceted process that can simultaneously include self-advocacy and reliance on services, thereby including some aspects of both social and medical models. We have previously proposed a framework for successful aging based on preventive and corrective proactive adaptations (Kahana & Kahana, 2003; Kahana, Kahana, & Kercher, 2003). This framework can readily apply to coping with stressors posed by disability in old age. Such coping efforts may range from concrete behaviors, such as environmental modifications and marshaling social support to psychological adaptations expressed through a reappraisal of one’s situation. Adaptations can also invoke altruism and spirituality as psychological resources that enhance well-being of older persons living with disability (Kahana, Bhatta, Lovegreen, Kahana, & Midlarsky, 2013). We also recognize that personal coping efforts, (considered by disability scholars as part of the medical model) must be complemented by significant policy initiatives that can empower older persons with disability and their families (Wacker & Roberto, 2013).

If we analyze the experience of an older person living with disability it is difficult to escape the conclusion that there are physical impairments and functional limitations that contribute to their disability (this is the domain of the medical model; Nagi, 1991). If we consider factors that facilitate late life well-being in living with disability, we must also look at physical and social environment and supports that make life easier or more difficult (domain of social model; Putnam, 2002). Given these medical and social circumstances, the daily lives of disabled older adults are also impacted by their personal adaptations as defined by active behaviors and cognitive orientations (Kahana & Kahana, 2003).

It is an all too common belief—among scholars and those writing books about aging well—that disability is separate from old age. The idea that natural aging processes somehow “cause” disability has little factual support; yet many people first experience disability in old age. How can the lack of a cause and effect relationship be understood in a way that is in harmony with the lived experience of older persons? How can older people best face their experiences with disability? How can adaptations enhance quality of life among older adults living with disabilities? And how can older people find meaning in life in the face of disability? We argue that proactive personal adaptations can empower older persons to live meaningful and satisfying lives with disability.

We begin with the premise that disability and aging are connected. Both have been stigmatized and yet also have the potential to reveal human strengths and resiliency. In this essay, we acknowledge that disability in old age differs from disability in younger populations. Younger people with disabilities lack a history as a nondisabled person and are more likely to see disability as a core aspect of their identity. This gives disability in old age a particularity, and helps us see that disability is a gateway concept—it opens doors to more clearly focus on the particular. This is needed because much of disability studies operates within a framework of generality. It is prevalent among disability scholars to use the “social model” as a comprehensive methodology suitable for all disabled persons, while eschewing all aspects of health or medical frameworks. The reality of physical impairments and functional limitations is thus relegated into the domain of a “reactionary” medical model (Shakespeare, 2006) Furthermore, there is little attention to the lived experience of disabled elderly persons.

There are challenges that lie in the way of integrating gerontological and disability studies perspectives. These include the reality that many older persons (even when disabled) opt to see themselves as not being disabled (Kelley-Moore, Schumacher, Kahana, & Kahana, 2006). Our position comes down in favor of accepting older adults’ self-definition, and recognizing the importance of personal autonomy and the dignity of risk. We do not take the position that all disabled people should maintain an approach that highlights pride and vigorous pursuits of legal and political rights based on a status of disability. Calling on a stress theory based approach that considers appraisals and coping (Kahana & Kahana, 2003), we highlight the life-course perspective as critical to understanding the nature of disability in old age. This life-course approach sees the linkages between a person’s past life, their present, and the future and it contextualizes late life within the social and cultural frameworks the person encountered in their earlier life (Dannefer, 2011). The life-course perspective also acknowledges the great importance of social ties in the framework of linked lives (Elder, 1994).

However, we also see the value of de-linking the present from the past, and the future in understanding late life disability. Too much emphasis on continuity in late life (Atchley & Barusch, 2004) can make disability and increasing functional limitations difficult to incorporate into one’s present concept of self. We try to show that the time of now is not the same as the time of the past, or the future—and here we emphasize personal adaptations that can enable the person to marshal resources and strength, and enlist the help of others. Examples of such adaptations are discussed in the remainder of this essay. We view them as markers of resilience in the face of late life disability.

**Exploring Resilience Among Older Adults Living With Disability**

In this essay, we consider older adults’ orientations toward aging with disability and offer examples, based on their perspectives on attaining resilience in the face of late life onset disabilities. We address the special challenges
faced by older adults who encounter disabling physical conditions in late life and endeavor to maintain meaning and good quality of life. We identify creative approaches to resilience and meaning making in the face of late life disability and explore the “disability paradox” (Albrecht & Devlieger, 1999) that highlights high quality of life among many frail older individuals who are living with disabilities. Yet, we also acknowledge perceptions of disability burden among older adults (Barry, Allore, Bruce, & Gill, 2009).

The concept of resilience has been primarily studied in the context of positive psychology and related to overcoming adverse effects of trauma (Seligman, 2011). It has been also a focus of attention in the nursing literature in relation to older adults (MacLeod, Musich, Hawkins, Alsgaard, & Wicker, 2016). Nurse researchers have also utilized this concept in the context of teaching resourcefulness to older adults who have experienced stressful life situations (Zauszniewski, 1997). Accordingly, to understand positive quality of life outcomes among older adults living with disabilities we must consider not only practical and behavioral adaptations, but also cognitive maneuvers that can help offer meaning to lives that include physical limitations and suffering. Such coping approaches comprise psychological orientations to dealing with disability (Aspinwall, 2011). In a qualitative study of old–old adults living with major disabilities, King and colleagues (2012) found that dignity and control were the key factors noted by respondents as defining their quality of life in the face of disabilities.

We recognize that models of disability are on a continuum regarding locus of control by the disabled older adult. The collective power of social movements that animates the social model of disability (Oliver, 1995) offers the greatest control. The expectation among young people with disabilities is that they are provided with funding to hire, direct, and supervise attendants to help them. There is also significant control by community dwelling older adults with disabilities who engage in individual adaptations in a home environment (Gitlin, 2003). These findings point to the continuing value of self-determination and choice for frail elders.

We must also consider unique needs of older adults, who live in long-term care facilities because of their disabilities. Life in long term care facilities offers the least personal control to those with disabilities (Kane et al., 1997). There are limited choices in such settings and residents’ lives are regulated by institutional rules that residents are expected to conform to. These older adults are dependent on support by often underpaid and overburdened formal caregivers (Olson, 2003). Such facilities may reinforce dependency and thereby undermine good quality of life (Baltes & Wahl, 1996). Even with some recent strides toward more resident-centered care, research on older adults living in long term care facilities documents the iatrogenic features of such settings (Kahana, Lovegreen, & Kahana, 2011).

To maintain good quality of life into their later years, older adults must engage in personal adaptations to live with their disabilities. Additionally, society must also make accommodations to improve lives of disabled older adults. Adaptations may be initiated by the older person or they may be facilitated by others, representing one’s social environment. Indeed, one of Zola’s (1982) major contributions to the study of disability has been the expectation that there be social inclusion of persons of all ages, who are living with disabilities.

Although older adults with disabilities are often part of the sample in diverse studies of late life, there are few studies that explicitly focus on adaptations to life with disabilities in old age (Hutcherson & Nimrod, 2012). Existing studies of adapting to late life disability are primarily qualitative explorations based on small purposive samples. Such studies have highlighted the importance of dignity and meaningfulness for older adults living with disabilities (Charmaz, 1995). Some quantitative studies (Gignac, Cott, & Bradley, 2000) have considered perceptions of independence as positive outcomes of successful adaptation to mobility limitations.

In our analyses of individual adaptations to late life disability, it is useful to build on theoretical approaches that have been previously applied primarily to the study of successful aging (Martin et al., 2015). Among the most relevant of these, we note Baltes and Baltes’ (1990) SOC theory, proposing selective optimization with compensation as useful strategies to build on existing strengths while recognizing limitations due to disability. Kahana and Kahana’s (1996, 2003) preventive and corrective proactive theory also offers useful orientations that recognize the value of health promotion, planning ahead, and helping others as useful preventive adaptations. Corrective adaptations address existing disabilities and include environmental modifications and marshaling support. Health care consumerism is noted as an emergent adaptation that comes closer to the social model of disability as older adults advocate for responsive care.

Given that disabled older adults typically need assistance with instrumental activities of daily living, we also recognize the unique task demands of being a successful care-getter (Kahana, Kahana, & Wykle, 2010). It has been argued that older people are often silenced in care discourses with little attention to their perspectives (Weicht, 2013). Consideration of active roles by elders with disabilities for marshaling support also brings us closer to the social model of disability that has been championed by young people living with disabilities (Shapiro, 1994). Nevertheless, we also acknowledge the general absence of collective action by older adults living with disabilities (Binstock, 2000).

To shed light on constructive coping strategies to deal with late life disability we must specify the many unique adaptive tasks that disabled adults must deal with. Adaptations can then be matched to specific task demands. Disability related adaptive tasks can be conceptualized as
similar to some of the to the illness adaptive tasks specified by Moos and Schaefer (1984). The latter include coping with discomfort and incapacity, preserving a reasonable emotional balance and preparing for an uncertain future. Goals of disabled older adults include maximizing comfort (reducing physical symptoms) and maintaining optimal functioning. To maintain psychological well-being, they must also strive to accept their disability while rejecting stigma. Additionally, they must maintain self-determination as care recipients and find dignity and meaning in the face of disabilities (Ryan & Deci, 2000).

**Examples of Resilient Adaptations to Living With Disabilities**

Here, we offer some illustrative examples of proactive coping strategies that can benefit older adults living with disabilities. These examples incorporate adaptations consistent with the social model as well as those more consistent with the medical model of disability. We have selected five examples from among adaptations proposed in the Proactivity Model of Successful Aging (Kahana et al., 2003): helping others, planning ahead, marshaling support, health care advocacy, and environmental modifications. We further add a dimension that is uniquely suited to dealing with disability: finding strength in spiritual or religious pursuits.

**Maintaining Dignity Through Helping Others**

Older adults living with disability often do not want to accept dehumanizing aspects of the medical model of late life disability (Kelley-Moore et al., 2006). They reject being considered as only recipients of care and not being able to offer any help or resources to others (Shield, 1988). One way they can seek empowerment is by finding helping roles, even while living with disabilities. Such roles are consistent with helping as a strategy of preventive proactivity outlined in the model by Kahana and Kahana (2003).

Sari Frost, the first author’s late mother was an amputee in late life. Soon after her amputation she learned that home health aides, paid through health insurance could only provide her with personal care as long as she was home-bound. Sari did not want to accept being doomed to lack of a meaningful and productive existence. She persevered until she could hire a helper who would enable her to cook from her wheelchair. She endeavored to maintain meaning in her life even as a care receiver. This included continuing engagement in productive activities and being a helper to benefit others. She hired a Hungarian immigrant who spoke only her native tongue. She suggested to her new helper that they should converse only in English to help the aide eventually get an education and obtain a better job. Feeling that she was a provider as well as a recipient of help made Sari feel like a “whole person,” in spite of her severe disability (Kahana & Kahana, 2017).

**Planning for Future Care to Promote Personal Control in Meeting Care Needs**

Being unprepared for increasing care needs and disability related limitations can create confusion and uncertainty and may lead to lack of personal control. An important preventive adaptation relates to planning ahead for increased care needs that are likely to arise among older persons living with disabilities (Kahana, Kahana, Bhatta, et al., 2019; Pinquart & Sorensen, 2002). Such future care planning (FCP) may involve marshaling support through conversations with family members, friends, and health care providers about anticipated resource availability, should care needs increase. Learning about high quality community services, such as home care, before acute care needs arise, can be highly beneficial in addressing diverse disabilities. There has been increasing attention directed at benefits of forward looking adaptations (Sudore & Fried, 2010). Specifically, the more of an active role the older adult plays in FCP, the more likely it is that their wishes will be respected and the care they will receive will be consistent with their preferences. FCP relates to the medical model in terms of focus on health care needs, but it also includes components of the social model by seeking accommodations through enlisting help of family members and service providers.

**Marshaling Intergenerational Support to Provide Technical Knowhow and to Empower Older Adults With Disabilities**

Help seeking from grandchildren or other young relatives can open up pathways to independence through technology. The “Mutuality Model of Grandparent–Grandchild relationships” (Kahana, Kahana, Kahana, & Goler, 2019) proposes that grandparents with disabilities seek accommodations from their own families by turning to adolescent and young adult grandchildren who can serve as mentors for skills needed for using technology. Adult children may be less likely to find time, given work and family obligations to provide such “nonessential” services. Grandparents can request targeted help for learning to retrieve health information, seek online resources, and communicate with health care providers using smart phones and computers. Getting “technical support” from grandchildren can also foster maintenance of meaningful relationships that can also yield emotional support. This type of adaptation is consistent with the social model by seeking accommodations through technology and fits with the medical model in addressing health related concerns.

**Obtaining Responsive Health Care Through Consumerism and Self-advocacy**

Persons with late life disabilities are no longer considered as full partners in medical care and are often excluded from shared decision making (Epstein, Fiscella, Lesser, & Stange,
Environmental Modifications to Improve Safety and Well-being of Older Persons Living With Disabilities

Most older adults want to age in place and continue living in their familiar surroundings (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Older people, who live with disabilities, may be able to extend community living through creative environmental modifications (Kahana & Kahana, 2017). According to the AARP (2010) “some simple modifications include adding nonslip strips to bathroom floors or other smooth surfaces, improving lighting, providing telephones with large numbers and letters, and installing grab bars and lever door handles.” Examples of environmental modifications also include rearranging furniture, so that needed items are easier to get to, “creating a command post” where frequently needed items are at hand. In reviewing research on the effectiveness of environmental modifications, Wahl, Fänge, Oswald, Gitlin, and Iwarsson (2009) found that functional abilities among older adults with disabilities can be improved by interventions to create a safe and comfortable environment, resulting in benefits consistent with the medical model.

Finding Strength in Spiritual and Religious Practices

Recognizing the salience of cognitive and psychological adaptations, there is an extensive literature discussing the value of spirituality and religiosity for enhancing well-being of older adults (Koenig, 2001; Pargament, Koenig, & Perez, 2000). Linkages of religiosity and spirituality to positive health outcomes in late life have been documented by Powell, Shahabi, and Thoresen (2003). Research done on older adults with disability in England (Kirby, Coleman, & Daley, 2004), indicates that spiritual beliefs offer a greater resource for frail older adults living with disabilities than they do for those who are not challenged by disabilities. Religious involvement has been found to moderate the adverse effects of disability on psychological well-being (Idler & Kasl, 1997). There has also been increasing attention in the field of medicine to the value of meditation and specifically mindfulness, as useful mechanisms for stress reduction in dealing with disability (Ludwig & Kabat-Zinn, 2008; Young & Baime, 2010). Indeed, these practices have been advocated as particularly useful for older adults as pathways toward resilience in the face of health-related challenges (Morone, Lynch, Greco, Tindle, & Weiner, 2008).

Toward Transcendent Goals in Adapting to Late Life Disability

In focusing on adaptations that can help older people live well with disabilities, we have considered the usefulness of various proactive adaptations, labeling some aspects of adaptation as more consistent with the social model of disability and others as more consistent with the medical model. These distinctions reflect our recognition that the lived experience of older persons is difficult to fully align with either of these prevailing models. The examples of individual adaptations we described above allow for alternative adaptive strategies, based on older adults’ values and preferences. Successful adaptations were also characterized by proactive orientations that call for older adults to continue seeking solutions based on their opportunities and preferences.

In the literature on disability and aging it is argued that older disabled persons are relegated to a more passive medical model of disability (Verbrugge & Jette, 1994). This may be due to their reluctance to get involved in social movements and engage in social advocacy on their own behalf (Kahana & Kahana, 2017). Yet, it must be recognized that the old live with far more limited time perspectives than do the young disabled. They have a foreshortened future and thus focus their energies on solutions that can yield rapid benefits (Kahana, Kahana, & Zhang, 2005). Their goals may also be viewed as consistent with Tornstam’s (2011) notions of gerotranscendence that involve finding meaning in more contemplative, legacy building orientations. This is also consistent with investing in fewer, but deeper relationships in late life, as proposed by Carstensen (1992) in her theory of socioemotional selectivity.

Perhaps the old are less concerned with oppressive social forces on the one hand (social model), and limitations imposed by their body on the other (medical model) than they are with maintenance of meaning and quality of life. Older adults and especially the very old, living with acquired physical disabilities have been found to define the good life based on connections with others, on developing positive traits and enhancing life regulation qualities (Dunn & Brody, 2008). These qualities echo Seligman’s (2003) notions, pursued in the Positive Psychology movement, regarding the universal human goals of a pleasant life and
a meaningful life. These characteristics are not directly addressed by the medical or social models of disability.

As noted in the disability paradox (Albrecht & Devlieger, 1999), maintenance of high quality of life near the end of life is infused with transcendent dimensions. We can learn much by listening to older adults as they find meaning in their lives, while living with disabilities and forge diverse individual pathways toward resilience and meaning making. Many people who at one time had ability—this is the aging with disability experience—will at a later point lose ability. When this happens and how it happens is unknown to most of us, yet in all likelihood it will happen.

Since most of the readers of this journal are students of aging, it might help to mention that the largest gain from the social model and the disability studies perspective is to help shift our perspective. Thus disability should not be treated and perceived as something that is wrong with the person, that is bad, and something we should avoid or compress. Disability represents an opportunity for personal growth and insight even if it also takes away aspects of ability and control. Indeed, thinking and talking about disability can make us have less fear about it, and give us courage. We believe that the discussion of disability should allow for disabled people of all ages—and especially the elderly—to be seen as having the right, power, and capability to fully engage in life.

In concluding our essay, we argue that there is no need to see either disability studies or gerontology as competing with one another from a disciplinary point of view. The real benefit of dialogue between the two fields is to the growth of both fields, and to older persons aging with disability, and younger persons with disability who are now aging. Disability and aging are truly interdependent—as are younger persons and older persons who are living with disability.

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Conflict of Interest

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