A critical analysis of health promotion and ‘empowerment’ in the context of palliative family care-giving

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Traditionally viewed as in opposition to palliative care, newer ideas about ‘health-promoting palliative care’ increasingly infuse the practices and philosophies of healthcare professionals, often invoking ideals of empowerment and participation in care and decision-making. The general tendency is to assume that empowerment, participation, and self-care are universally beneficial for and welcomed by all individuals. But does this assumption hold for everyone, and do we fully understand the implications of health-promoting palliative care for family caregivers in particular? In this study, we draw on existing literature to highlight potential challenges arising from the application of ‘family empowerment’ strategies in palliative home-care nursing practice. In particular, there is a risk that empowerment may be operationalized as transferring technical and medical-care tasks to family caregivers at home. Yet, for some family caregivers, a sense of security and support, as well as trust in professionals, may be equally if not more important than empowerment. Relational and role concerns may also at times take precedence over a desire for empowerment. The potential implications of ‘family empowerment’ are explored in this regard. ‘Family empowerment’ approaches need to be accompanied by a strong understanding of how to best support individual palliative family caregivers.

Key words: empowerment, family care-giving, health promotion, palliative care.

Family members play a critical, and arguably, the most prominent role in supporting those choosing to die at home (Arras 1995; Rabow, Hauser, and Adams 2004). Palliative family caregivers perform their work within the context of formal services, such as home-care nursing, that are increasingly rooted within health-promoting models. While until recently, palliative care and health promotion were viewed as opposite ideas, the broadness of the definition of ‘health’ as including ‘well-being’ and ‘quality of life’ has been used by Kellehear (1999) and others (Russell and Sander 1998a,b; Lloyd 2000; Buckley 2002; Raudonis 2003; Miller and Ryndes 2005) to advocate for a ‘health-promoting’ palliative care practice. While tending to advocate a variety of ways to enhance health and well-being, the dominant emphasis in health promotion has been on strengthening the capabilities of individuals to control their health. This manifests in ideas about and practices related to patient and family empowerment, self-care and family involvement in care ‘partnerships’.

We maintain that the application of ‘empowering’ health promotion approaches in palliative care can have important implications for family caregivers who are often considered part of the unit of care. The general tendency is to assume that health promotion’s emphasis on empowerment, participation, and self-care is universally beneficial for, and welcomed by, all individuals. But does this assumption hold for everyone, including palliative family caregivers? In this study,
we explore the concept of health-promoting 'family empowerment' in the context of palliative home-care nursing practice with family caregivers, drawing on existing research and practice exemplars to highlight potential challenges. Specifically, there is a risk that empowerment may be operationalized in practice as encouraging the transfer of more and more technical and medical-care tasks to family caregivers at home. The potential implications of such an approach are explored. As such, there is a need for caution when applying health promotion approaches and strategies (such as 'family empowerment'); such work needs to be accompanied with a strong understanding of how to best support individual family caregivers in palliative care contexts. We conclude with discussion about how awareness of the risks (as well as opportunities) involved can help inform the operationalization of the concept in practice.

HEALTH PROMOTION IN PALLIATIVE CARE: BACKGROUND

As a concept and set of practical strategies, health promotion is a process of enabling people to take action and exert control over the determinants of health and thereby improve their health. This involves strengthening the skills and capabilities of individuals and/or communities to take such action (World Health Organisation 1986). Specific health promotion strategies vary widely depending on the specific determinants they address (e.g. individual health behaviors, socio-economic or environmental contexts, etc.), and the extent to which they are ‘top-down’ (such as developing healthy public policies) or ‘bottom-up’ (such as community development). However, the majority of health promotion targets individual behavior changes, most commonly in the form of health education and promotion of self-care.

Until recently, health promotion and palliative care were viewed as opposite ideas. Kellehear (1999, 77) proposed a health-promoting approach to palliative care designed to ‘enhance a sense of control and support for those living with a serious life-threatening illness’. Like Kellehear, others (Russell and Sander 1998a,b; Lloyd 2000; Buckley 2002; Raudonis 2003; Miller and Ryndes 2005) now advocate a health-promoting approach in palliative care, often through involving patients more actively in their treatment and decision-making. Movement towards palliative home care was even motivated in part by the perception that greater freedom and control could be provided in the home environment (Stajduhar and Davies 1998).

Empowerment is identified by Robertson and Minkler (1994) as the core concept behind the health promotion movement that stemmed from Lalonde (1974) and the World Health Organisation. Representing the ability to control and/or participate in one’s life or environment (Robertson and Minkler 1994), empowerment is valued not only for promoting physical and mental health (e.g. through perceived control and self-efficacy), but also for enhancing the quality of care, representing an essential element of the civil right to autonomy, and purportedly for addressing power inequities. Within the context of palliative care nursing, empowerment is institutionalized in the movement towards partnership models of care with patients and families, and towards promoting patient and caregiver autonomy and participation in care, treatment, and decision-making (e.g. Russell and Sander 1998a,b; Kellehear 1999; Lloyd 2000; Buckley 2002; Pegg and Tan 2002; Richardson 2002; Amella 2003). Overall, however, the emphasis appears to be on patient involvement; there is much less consideration of the specific benefits and implications of health-promoting palliative care and empowerment for family caregivers. This is despite the fact that family caregivers themselves face considerable health risks, including physical, emotional, social, and financial distress (Steele and Fitch 1996; Schulz and Beach 1999; Cameron et al. 2002; Grande et al. 2004; Zarit 2004). Instead, there tends to be an assumption that family members will themselves be empowered through training and education designed to involve them not only in decision-making, but in patient care, and that this will enhance their own sense of control and health.

We are not arguing that health-promoting palliative care lacks a place within philosophical approaches to care of the dying. We agree that this approach can have significant benefits when applied to dying patients. Our intent is to further explore the implications of ‘family empowerment’ in palliative home-care nursing. We seek to highlight the potential challenges and risks involved in such approaches, for family caregivers, and suggest need for discussion about the particular ways in which empowerment is operationalized in home-care nursing.

EMPOWERMENT AND FAMILY CARE-GIVING: THE CHALLENGES

Despite some evidence that lay persons have different ideas about what it means to be empowered (Johnston Roberts 1999), the interpretation of empowerment tends to occur at the level of healthcare service policy and practice management, in the form of healthcare interventions and delivery approaches. Yet empowerment is an abstract ideal, and there is a lack of clarity around what strategies are empowering, as
well as ‘what actually is covered by the term ‘enabling role’ and what kinds of skills are required to perform such a role’ (Andrews 1999, 280). Most commonly, empowerment has been operationalized into health education designed to empower patients to perform more self-care, as well as into promoting ‘empowering’ interactions between patients and providers (i.e. a shared distribution of power: Johnston Roberts 1999). However, how ‘family empowerment’ in particular is enacted in clinical practice, within organizations and by practitioners, is often unclear. It could mean, for instance, activating family caregivers as ‘co-workers’ in a partnership care model, involving them in direct care provision (Ward-Griffin and McKeever 2000; Ward-Griffin and Marshall 2003), or involving them in decision-making about patient care (Drought and Koenig 2002).

Many others have explored the phenomena whereby family members are encouraged to participate in a patient’s care and decision-making, although the phenomena are not always explicitly linked to ideas about health promotion or empowerment. For example, Ward-Griffin and McKeever (2000, 95) describe home-care nursing strategies to contain costs, including ‘delegating as much care as possible to the family caregiver’ and ‘gradually decreasing the frequency and range of care’. Gregor (1997) argues that sustained cost constraints have necessitated shifts in home-care nursing practice away from nurses providing direct care to teaching family members how to provide care. Studies suggest that nurses are under pressure to limit their services (Ward-Griffin and McKeever 2000; Purkis 2001), often at the expense of providing sufficient assistance to family caregivers (Bjornsdottir 2002). Purkis (2001) found that home-care nurses are faced with daily decisions related to the rationing of the services they provide to families. This environment has resulted in a situation where nurses are not always able to deliver the care requested or even required (Ellenbecker and Warren 1998). In the absence of adequate resources to support family members in their care-giving roles, nurses are required to shift the primary responsibility for care to family caregivers. A central way to accomplish this is to empower family members to take on more and more responsibility for care.

However, the ways in which health promotion, and empowerment in particular, are linked to the downloading of responsibilities are complex, often indirect, and difficult to identify through traditional research methods that focus on the individual as the unit of analysis (as opposed, for instance, to methods such as institutional ethnography). As Purkis, Ceci, and Bjornsdottir (2008) note, while the neoliberal vocabulary of choice and related ideals such as individual autonomy, self-help and personal responsibility might seem far removed from the transfer of tasks to family caregiv-

**Consumer-driven empowerment orientation: practice exemplars**

The extent to which a consumer-driven empowerment orientation is currently in play in palliative nursing contexts remains to be confirmed in empirical research. In this study, we draw on ‘practice exemplars’ in a western Canadian context, to suggest that in fact, home-care nurses might inadvertently play a role in this process. Specifically, these selected exemplars illustrate how health promotion ideals such as empowerment might be linked to service.

First, home-care nurses appear to some extent to link ideas of autonomy with ideas about limiting access to services. One home-care nurse spoke about the emphasis on self-care in the community for her non-palliative clients, suggesting that offering too much support (e.g. daily visits) would promote dysfunction. While this nurse expressed that palliative clients and families would have more of a say about visits, when speaking more generally about her practice with all clients, she expresses how family caregivers are often doing care, dispensing pills, and giving suppositories or other bowel care. She suggests that if the family caregiver could not perform these tasks she would step in, but that they try instead to empower family caregivers to do this care. Likewise, one home-care nurse spoke about how the anxiety of dealing with terminal illness means that some family ask for all the service they feel they are entitled to; if the nurse concedes, she may in fact be hampering their growth and promoting panic and helplessness. To some extent, there was a greater tendency for this kind of emphasis on self-care, empowerment and autonomy with respect to non-palliative

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1 Excerpts are drawn from qualitative data collected from 27 home-care nurses, who were interviewed in-person about their interactions with family caregivers, and families’ access to home-care nursing visits.
clients and families, suggesting that nurses’ beliefs about the vulnerabilities involved in dealing with a terminal illness may serve as a buffer in this regard.

It was also common for home-care nurses to emphasize letting the family make their own decisions and choices, and this was most often invoked with reference to clients and families that resist services. The overwhelming sentiment was that the best approach is to respect the family’s autonomy. One nurse expresses her concern that palliative clients/families will resist asking for services, struggling through on their own. She refers to how the home-care nursing role is about promoting independence, and she wonders, from a practice perspective, if this is why nurses may just leave the onus on the family to call if they need help.

It is possible that such phenomena may represent a ‘mis-directed’ form of empowerment that does not appropriately reflect the goals of health-promoting palliative family care. Indeed, some research focuses on home-care nurses’ misinterpretation of the meaning of empowerment and blame poor implementation on their resistance to giving up control and power (McWilliam et al. 2003; Strober 2005). Similarly, Brown, McWilliam, and Ward-Griffin (2006, 164) found that ‘rather than assisting clients in exploring, deciding and evolving their role as partners in care, [nurses] understood the new approach as meaning that clients had to survive the healthcare system on their own’. However, it is also possible that home-care nurses receive conflicting messages about empowerment in service delivery, and that ‘mis-interpretation’ does not lie only at the level of the individual nurse. There is a need to critically examine how empowerment is implemented within policies, at the management level, as well as in practice by home-care nurses working with palliative family caregivers.

**POTENTIAL IMPLICATIONS FOR PALLIATIVE FAMILY CAREGIVERS**

In the remainder of this study, we explore the potential implications of the particular approach to ‘family empowerment’ described here. Implicit in many empowering approaches is an assumption that all individuals desire active involvement in all aspects of care provision and decision-making. Yet the literature to support this assumption is inconclusive. In fact, research with acute care patients, long-term care facility residents, and to a lesser extent, family caregivers, suggests not everyone desires active involvement in care provision and decision-making (Benbassat, Pilpel, and Tidhar 1998; Ward-Griffin and McKeever 2000; Funk 2004). For instance, Drought and Koenig (2002, 114) reported that shared decision-making at end of life is ‘illusory’ in practice due in part to resistance from patients who ‘hold other values more important than autonomy’. Thus, while some family members may welcome the sense of control involved in empowering and participatory approaches, an empowering approach may not always be desired. Not only is a sense of support/security and trust equally if not more important than control for some family caregivers and in some situations, but in addition, empowerment approaches may conflict with a desire to protect family relationships, and family caregiver roles may conflict with family member roles. While most of the literature in this area focuses on patient experiences with empowerment with more limited attention on family caregivers, we draw on both sets of literature to inform our arguments.

**A sense of security may be more important than empowerment**

First, in some situations and/or among some individuals, a sense of security that comes from feeling supported may be equally if not more important than empowerment. For instance, Lloyd (2000, 183) expresses caution in relation to health promotion with palliative patients:

> an over-simplistic view of how people exercise choice and control over the process of dying overlooks the importance of the comfort that older people may derive from knowing that they are in the hands of professionals who are competent and know them well.

Likewise, Richardson (2002, 438) found that palliative patients valued ‘egalitarian’ personal relationships with nurses, but equally valued professional nurse-led relationships that provided not only advice and guidance, but also practical assistance with care; her research also highlights the importance of ‘the feeling of safety and security derived from the nurses’ involvement’ and availability or presence.

Other research documents family members’ anxieties, fears and tension ‘linked to assuming the responsibility for administering the care’ of patients after early hospital discharge (Guberman et al. 2005), or when they perceived that they were left on their own to provide the majority of care, and more than they were comfortable with or felt prepared to do (Ward-Griffin and McKeever 2000). Indeed, some family members may feel pressured to provide palliative home care, are reluctant to do so and resist, sometimes unsuccessfully, taking on care they feel is the responsibility of healthcare providers (Stajduhar 2003; Stajduhar et al. 2008b). Where empowering approaches seem to be more successful
is in instances where caregivers do not feel abandoned in the care-giving process (Mok et al. 2002). Stajduhar et al. (2008a), in a study of family caregivers of terminally ill cancer patients, found that the caregiver’s sense of security (e.g. ‘knowing the system will be there when they need it’) is a key aspect of their ability to cope. Further, the findings from a systematic review of family members’ situations and needs for support in end-of-life care (Andershed 2006) demonstrates the significance of family members’ need for safety and security (Öhleen et al. 2007). It would seem then that greater support from the healthcare system, as opposed to empowering caregivers to take on further responsibilities of the healthcare system, might be a more useful approach in supporting family caregivers.

**Trust may be as important as empowerment**

Relatedly, trust in professionals may be equally as important as empowerment for some individuals and in some situations. Some research suggests that individuals coping with psychosocial impacts of severe, acute conditions may prefer to place trust in health professionals (Benbassat, Pilpel, and Tidhar 1998) and have decisions made by them in some cases. Rational human responses to the psychological and emotional effects of terminal and/or severe, acute illness include an enhanced need for trust and ‘secondary’ control (Rothbaum, Weisz, and Snyder 1982), and have been suggested to account for lowered desire for personal control or active involvement (Waterworth and Luker 1990; Donaldson, Lloyd, and Lupton 1991; Anderson 1996; Lupton 1997). For instance, preference for active, participatory roles in medical decisions decreases with increasing illness severity (Thompson, Pitts, and Schwankovsky 1993; Catalan et al. 1994; Benbassat, Pilpel, and Tidhar 1998); in research with terminally ill patients, Puchalski et al. (2000) noted that 70.8% preferred to defer decision-making to family members and physicians if they were to lose decision-making capacity. Kellehear (1999, 17) himself emphasizes that promoting the choice and active involvement of patients ‘may involve a conscious decision on the part of some people to surrender themselves to a traditional, dependent ‘sick role’.

While there are very few studies on family caregivers’ explicit desire for trust, terminal illness in a family member is associated with uncertainty, loss, anxiety, and fear in family caregivers. Heyland et al. (2003) indicate that 14.8% of substitute decision-makers for terminally ill patients reported preferring to leave all decisions to the physician; 23.8% preferred the physician make the final decision after considering their opinion. In another study of both terminally ill patients and family members (Heyland et al. 2006), having ‘trust and confidence in the doctor looking after the patient’ is of primary importance. While the extent to which a desire for trust is part of ‘normal’ family caregiver coping remains to be more fully examined, it suggests the need to consider the implications of the palliative family care-giving for experiences of empowerment.

**Relational concerns may take precedence over a desire for empowerment**

In addition to concerns about being supported and trusting in professional competence, family caregivers also have relational and role concerns that may at times take precedence over a desire for empowerment. For example, in one study (Funk 2010), adult children supporting aging parents emphasized a need to respect their parent’s autonomy, drawing the boundaries of their responsibility to parents by criticizing controlling care-giving behavior. For example, one daughter spoke of how her mother’s homemakers expressed that she should make her mother (who had dementia) take her medications (mostly vitamins): they ‘have these expectations of, … my daughter role, in that somehow I’m gonna be able to make my mom do the things that she should do, because, that’s my role. And of course, I don’t feel like that’s my role’ (Funk 2010). Adult children were uncomfortable taking an active role in care where parents resisted this help; for instance, such adult children might prefer that an outside professional would step in, in order to help the adult child protect their relationship. These findings are confirmed in other studies which also suggest sons and daughters place particular importance on maximizing a parents’ independence and autonomy and not taking control (Abel 1990; Allen and Walker 1992; Braudy Harris and Orpett Long 1999; Sheehan and Donorfio 1999); such as through ‘backing off’ or relinquishing certain aspects of care (Piercy 1998; Caron and Bowers 2003). Abel (1990, 198) concludes that taking control crosses ‘a sensitive boundary in parent–child relations’. Taking on roles that one is not used to or comfortable within, in this context, can create stress for family caregivers, particularly in the context of their filial relationships.

Empowerment may therefore not coincide with expected roles, and/or may fuel role conflict. Family caregivers’ receptivity to and satisfaction with empowerment likely depend on role expectations (Heinrich, Neufeld, and Harrison 2003). Stajduhar et al. (2008b) found that some family caregivers situate themselves as co-workers and seek an active role...
within the hospice palliative care team. Others, however felt situated as co-workers by a healthcare system with limited resources, and expressed feeling unprepared yet expected to provide care, and frustration at doing what they viewed was the work of professional providers (such as administering pain medication). Consideration of family members’ role preferences at the end of life is particularly important. For instance, what are the implications of ‘empowering’ a daughter to take on the role of primary caregiver for her dying mother, where this encroaches on her ability to function within her ‘daughter’ role? In a qualitative exploration of home-based palliative care-giving (Stajduhar 2003), while some family members took pride in new, ‘nurse-caregiver’ roles in patient care, others indicated that this role changed their family relationships and took time away from other family roles and identities. For example, having to inflict unpleasant medical procedures on her father was difficult for one daughter, because her father was angry at her for this. This daughter expressed the resulting sense of role confusion:

instead of your job being to just sit there, spend time with him, comfort him, and hold their hand, suddenly your job is to look after their pain, their nourishment, their bodily functions. So, you feel like you don’t really know what exactly it is you should be (p. 30).

In addition, family members who provided intimate personal-care tasks explained how they had to emotionally disengage from such activities due to feelings of embarrassment (Stajduhar 2001). And, as one family member described, ‘you become a different person, you stop being a wife and you start being a caregiver and a professional’ (Stajduhar 2001).

**DISCUSSION**

In the context of the erosion of formal services that have occurred in many countries over the last few decades, the role of informal caregivers in promoting the health of terminally ill individuals is becoming increasingly salient. However, there is little acknowledgement of their role ‘behind the scenes’ in what is assumed to be patient ‘self-care’. Instead, there is an assumption that empowering the patient is synonymous with empowering the family caregiver. The institutionalization of empowerment within home care, and its tendency to be uncritically accepted as ‘good for everyone,’ has implications for both family caregivers and formal providers, particularly in the context of end-of-life care. While we acknowledge that not all models of health-promoting palliative care focus solely on ‘empowerment’

nor ignore family caregivers, our review in this area suggests the potential that where health-promoting palliative care is interpreted as involving family as fully in the care of the patient as possible (justifying the removal of formal services), that this may have unintended negative consequences.

For many complex reasons family caregivers may resist greater involvement in care tasks or decision-making; as such, we need to explore the potential risks involved in an empowerment philosophy of care, particularly where it is operationalized as transferring responsibility, tasks and decision-making to family caregivers at home. This kind of empowerment may cause difficulties for family caregivers who desire to feel secure and supported, trust healthcare professionals, or prefer a role with less care-giving involvement (a preference that may be closely tied to their desire to protect their relationships and avoid potential conflicts between care-giving and family member roles). For these individuals, promoting their active involvement may contribute to feeling unsupported or isolated, a lack of trust, disrupted family relationships and dynamics, and role conflict. It suggests the potential for negative experiences, dissatisfaction and resentment (e.g. it may be interpreted as a lack of care from the health system), coping difficulties, anxiety, fear, and frustration. There may also be feelings of guilt among family members where their involvement entails ‘enforcing’ care upon parents who resist, or where family members feel they do not meet the expectations of the healthcare system. To make palliative care-giving at home a reality for those who want it, caregivers have to genuinely want to provide care rather than being pressured into providing it; they also need to feel they can get support from the healthcare system when needed. Encouraging empowerment for family caregivers who do not desire it may cause stress and discomfort, promote dissatisfaction, be interpreted as a lack of care, and may even be unethical (Waterworth and Luker 1990; Ashworth, Longmate, and Morrison 1992).

More broadly, just as health promotion’s emphasis on the moral imperative of health and individual responsibility can stigmatize the ill (Labonte and Penfold 1981; Lupton 1993; Renaud 1994), it may also emphasize a healthy death and stigmatize family caregivers who cannot cope with the demands of providing palliative care in order to facilitate a healthy death. It also obscures and diverts attention from the broader social and economic determinants of well-being in terminal illness. While both patients and caregivers are not passive recipients of services, we must also acknowledge that there are varying levels of individual capacities and desires to provide care for terminally ill family members; such capacities are also influenced by factors such as
conclusion

Clearly, there are obvious benefits to considering a health promotion perspective in palliative care. Yet the ways in which health promotion, and specifically, the concept of empowerment, have been interpreted and applied within home-care practice can be problematic for family caregivers. A critical, and more than superficial, understanding of both the opportunities and potentially harmful implications of ‘family empowerment’ as a form of health-promoting home-care nursing services is required. Unless this occurs, we jeopardize our ability to create and develop policies and services that effectively promote the well-being of not only the dying individual, but also the family caregivers who provide support during end-of-life.

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‘gender, class, generation and culture as well as health’ (Barry 1995, 372).

The extent to which family members desire and welcome increased participation in the care and decision-making of terminally ill patients at home needs to be confirmed in research: we currently lack comprehensive evidence on how empowerment is experienced by family caregivers, as opposed to patients, and on individual variations in preferences and beneficial outcomes. Further, there is a lack of knowledge regarding the enactment and experience of empowerment in palliative contexts. Regarding the latter, it should be acknowledged that ‘empowerment’ is a contested concept (as is health promotion), particularly in terms of what it would look like in practice. We are therefore not suggesting that empowerment and health promotion in palliative care will not benefit any family caregivers. Indeed, in one intervention, families learned how to navigate biomedically culture, which they described as empowering (Strober 2005); in another, families of hospitalized elderly became more involved in care and reported greater role reward (Li et al. 2003). Further, support, in the form of service, need not be considered antithetical to empowerment; in fact, the lack of support might be detrimental to health promotion: for example, Anderson (1990) emphasizes how the lack of formal services for families coping with chronic illness is a barrier to effective self-management and health promotion. In addition, McWilliam et al. (2001) suggest resource limitations undermine empowerment in home care. Likewise, support and service can be provided in ways that have empowering outcomes, as, for instance, Stoltz (2006) suggests. In addition, empowerment could involve ‘relational’ autonomy (as opposed to ‘individual autonomy’), which acknowledges the interdependence in relationships (Christman 2004) between home-care nurse and family caregiver, and emphasizes mutual decision-making (cf., e.g. Öhlén et al. 2006).

Lastly, we should consider the implications of a ‘public health’ dimension of health-promoting palliative care when developing strategies to ‘empower’ clients and families. Kellehear (1999) suggests all of the following should be addressed together: health and death education and information; social supports (i.e. support groups) and community services; interpersonal skills and problem-solving support (e.g. promoting self-help in lay groups of patients); reorienting health services; and combating death-denying policies and attitudes. Accordingly, a public health perspective on ‘empowerment’ would emphasize the need to consider the long-term effects of care-giving, rather than the short-term effects (caregivers managing to conduct as much care as possible).


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