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Dysphagia and the Family

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<http://dx.doi.org/10.5772/60856>

1. Introduction

The medical effects of dysphagia, including dehydration, malnutrition, and aspiration, that lead to pneumonia are well documented throughout the literature, as are the negative consequences of dysphagia on an individual's functioning and quality of life. What is less known, however, is how the family members of people with dysphagia are impacted by this condition. Understanding the issues faced by individuals who support and care for family members with dysphagia, and exploring how health professionals can best support the needs of the entire family is an important and emerging area of both research and clinical practice.

2. The biopsychosocial effects of dysphagia

Dysphagia is traditionally defined as a difficulty or abnormality in swallowing. In adulthood, it is predominantly an acquired condition and may result from a wide variety of etiologies. It can also result from changes associated with the effects of normal aging [1]. Over the past four decades, the bulk of research conducted in the field of dysphagia and its management has focused on understanding this condition at an impairment level. Through this historical body of work, swallowing is now understood to be a complex physiological process that involves precision timing and coordination of multiple structures within the neuromuscular system. Oropharyngeal dysphagia can be associated with a range of physiological impairments, which may lead to difficulty in oral preparation of the bolus, moving the bolus posteriorly toward the pharynx, triggering and coordinating the pharyngeal swallow, clearing the bolus into the upper esophagus, and protecting the airway from food and fluid entry [2]. Depending on the etiology of the condition causing dysphagia, individuals may also be affected by associated impairments such as xerostomia (dry mouth), taste changes, or excessive secretions that may

further impact capacity, motivation, and desire to eat. The associated medical effects resulting from difficulty in swallowing may include dehydration, malnutrition [3], and respiratory dysfunction (including pneumonia) [4], and ultimately can lead to death in severe cases [5].

The traditional management approaches that have evolved in parallel with our understanding of the process of normal swallowing have also been predominantly based on impairment. Interventions including postural strategies, swallowing techniques, and modification of food and fluid textures are used as first-line treatment options to compensate for specific physiological impairments and to improve the efficiency and safety of oropharyngeal swallowing function. Active rehabilitation programs, which are typically implemented in parallel to compensatory measures, are developed following a combination of clinical and objective assessments (videofluoroscopy or fiber-optic endoscopic evaluation of swallowing) and involve behavioral and medical interventions designed to improve swallowing physiology for long-term gain.

While management services for adult-acquired dysphagia remain predominantly focused on remediating physiological impairments, in particular, the need to consider the wider psychosocial impacts of dysphagia has been highlighted in the past decade. It is now recognized that health professionals must consider dysphagia and its effects more broadly, and that dysphagia is, in fact, a multifaceted condition. In addition to its impact on the medical condition of the individual, dysphagia has also been demonstrated to effect functioning in daily life and overall quality of life [6]. Eating and drinking is a source of human pleasure. Dysphagia can make this process and the activities surrounding it laborious, uncomfortable, and difficult [7]. Irrespective of the cause, dysphagia has been found to have a significant negative impact on the quality of life both immediately and months or years following its onset [5, 6, 8]. In the geriatric population, reduced quality of life has been associated with self-perceived swallowing difficulties, a condition that older people did not necessarily associate with normal aging [9].

Recent studies have also demonstrated the impact of dysphagia on psychosocial health. In a population-based study, dysphagia was reported by 16% of those surveyed, with intermittent dysphagia associated with anxiety and progressive dysphagia associated with depression [10]. Anxiety and depression are also significantly worse in head and neck cancer survivors with dysphagia than those without dysphagia, irrespective of treatment type [8, 11]. For people with dysphagia, difficulty in swallowing has been found to affect socialization, eating out, family rituals, cooking, and shopping [12-14]. As such, the concept of dysphagia needs to be reconsidered. Dysphagia is more than simply a physical difficulty. Rather it represents a complex and multilayered condition that may impact on a person's physical, emotional, and social life and carries significant burden surrounding functioning in everyday activities.

In order to embrace a wider view of dysphagia, a new conceptual framework is required. The International Classification of Functioning, Disability and Health (ICF) [15] (Figure 1) has been both proposed [16] and used [17-21] as a consistent and universal taxonomy to report research outcomes regarding dysphagia. The ICF is a conceptual framework that provides a biopsychosocial perspective of functioning, and uses an internationally recognized language [15]. It has the potential to describe the far-reaching complexities of dysphagia through the consideration of functioning from the perspective of the body, the individual, and society in two

parts: (1) functioning and disability and (2) contextual factors [15]. Functioning and disability comprises (a) the body functions and body structures and (b) activities and participation. The contextual factors are comprised of (a) environmental factors and (b) personal factors (WHO, 2001) (Figure 1).

Each of the components of the ICF consists of various domains and categories that are referred to as the units of classification. Therefore, the functioning of an individual with a health condition can be documented using the appropriate category code and then adding qualifiers, which are numeric codes that specify the magnitude of the individual's functioning or disability within that category [15]. An alphanumeric coding system is used for coding health conditions in the ICF. The letters *b*, *s*, *d*, and *e* represent body functions, body structures, activities and participation, and environmental factors respectively. A numeric code then follows these letters, which denotes the domain (or chapter number), followed by additional sublevels of coding, and then the qualifiers (WHO, 2001). For example, changes to taste would be linked to the code b250 - taste function where *b* represents the body functions domain and the numbers (i.e., 250) represent the various levels of classification.

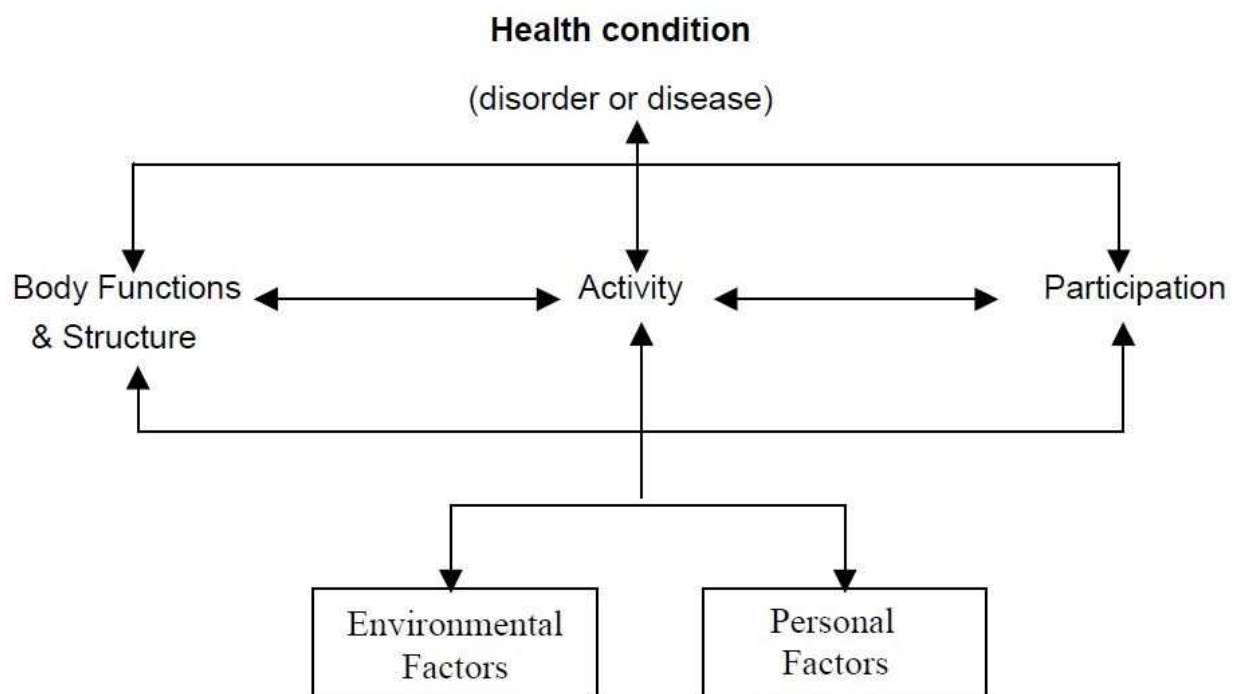


Figure 1. International Classification of Functioning, Disability and Health (ICF) [15]

Recently, a study examining the consumer's perspective of living with dysphagia following management for head and neck cancer utilized the ICF to classify patients' physical, emotional, and psychosocial concerns relating to their dysphagia [20]. The results demonstrated that dysphagia impacted on body functions, activities and participation, and environmental factors almost equally, with changes to body structures rarely mentioned by people with dysphagia. Therefore when dysphagia is examined more broadly, using a framework such as the ICF, it

clearly has far-reaching life effects beyond the physiological changes to the swallow and the medical implications of dysphagia.

3. The effects of dysphagia on the family

Mealtimes, eating, and drinking are profoundly social activities that sustain not only our physiological needs but also our social and emotional life [22]. The meanings we attach to food, and the processes of eating and swallowing are deeply connected to our most valued activities and experiences, and are integral to how we see ourselves as individuals and in relation to others [23]. As such the negative effects of dysphagia are recognized to influence more than just the life of the person with the condition.

In a recent study that mapped the experiences of living with dysphagia following nonsurgical head and neck cancer management to the ICF, a number of environmental factors were identified to influence the functioning (and disability) of the individuals with dysphagia [20]. In particular, family members were identified as important sources of support for people with dysphagia throughout the trajectory of care, particularly in regards to meal preparation and the encouragement to keep eating [20]. In addition to playing an important support role, there is emerging evidence to indicate that families also experience negative effects as a result of living with and supporting individuals with dysphagia [24-26]. For the purposes of this chapter, family is defined as any individual who plays a significant role in the life of the person with dysphagia. This definition encompasses a broad concept of family, and is consistent with other literature, whereby family is described as being two or more people who are related in any way, including through a continuing biological, legal, or emotional relationship [27].

Recent research has demonstrated the pervasive effects of dysphagia on family members following a number of different etiologies including head and neck cancer treatment [24, 26, 28, 29], stroke [25], traumatic brain injury [25], and motor neuron disease [30]. This body of evidence has revealed that families are important members of the support team for people with dysphagia as they provide valuable practical and emotional support. The high levels of burden experienced by family members in relation to food and meal preparation may hinder their ability to function effectively as a support system for the individual with dysphagia [24, 26, 31]. It can also affect their physical and psychological health, and quality of life [24, 25, 32].

Verdonck de Leeuw et al. [32] found that the presence of a gastrostomy tube, a surrogate indicator of dysphagia, in people with head and neck cancer was the only significant predictor of distress in family carers. Supporting this, the family members of people with head and neck cancer and dysphagia have been shown to experience a reduced quality of life both before cancer treatment and in the early acute phase, with significant improvements shown between 3 and 12 months post-treatment [24]. Evidence supports that the family member's quality of life was found to significantly correlate with the functioning of their family member with dysphagia [24]. Therefore, the presence of dysphagia has the potential to have significant effects, not only on the life of the person with dysphagia but also on their family. Despite

differing etiologies, family members of people with dysphagia consistently report negative effects on their everyday lives as a result of the dysphagia particularly in relation to: managing modified diets/fluids, and providing appropriate meals; negative influences of dysphagia on family dynamics and social activities; and the emotional impacts of dysphagia [24-26, 28-30].

3.1. Managing modified diets and fluids and providing appropriate meals

A number of studies have noted that family members of people with dysphagia report experiencing distress associated with food preparation and mealtime activities [24-26, 31]. Consistently across multiple studies, family members reported changes to their meal preparation, noting a need for more conscious and intentional thought and planning, and the need to cook two separate meals [24-26]. Preparing food and meals is one of the most significant ways of providing care, and demonstrating love and concern for others [22, 24, 33]. Though often discounted as trivial, there are a number of important skills involved in the work of “feeding the family” [22]. These skills include: planning meals, learning the food preferences of others, learning about food and preparation techniques, provisioning and shopping for food, preparing meals, serving meals, feeding, and cleaning up from meals.

Meals have been described as fundamental to our daily thinking and acting and are core component to how we organize our days [34]. It has been estimated that the average person makes over 260 decisions a day regarding eating and that more than 200 of these choices are made subconsciously [35]. When it comes to preparing meals for an individual with dysphagia, decisions regarding eating and drinking are likely to increase and will likely no longer be subconscious. Putting a meal together requires more than cooking as it takes “thoughtful foresight, simultaneous attention to several different aspects of a project, and a continuing openness to ongoing events and interactions” (p. 55) [22]. When a family member has dysphagia, putting a meal together becomes a more intense and time-consuming process [26].

3.2. Influence of dysphagia on family dynamics and social activities

Dysphagia has a recognized influence on family dynamics [24-26, 30, 31]. Many families report the need to accommodate the needs of their family member with dysphagia and consistently find a disruption to family mealtimes [26]. For a number of families, their meals are now dictated by what their family member with dysphagia can eat and some families also eat textured modified diets [26]. In addition, several families have commented that they no longer ate meals together as they did not want to eat in front of their family member with dysphagia [26, 30]. Those that did reported changes to the meaning and experiences of family meals [24-26]. In some studies family members reported leaving the dinner table because they could not cope with their family member’s dysphagia [25, 26]. Family mealtimes are often acknowledged as an important get-together time to enrich family life and “eating together means staying together” (p. 11) [34]. When one member of the family can no longer fully engage in the mealtime experience because of dysphagia, the effects are felt by the entire family unit as there is a loss in the social bonds of food and meals [24-26, 30, 31].

The effects of dysphagia, on family members at mealtimes, are not limited to the home. Numerous studies have documented the negative effects of dysphagia on family member's social lives including eating out at restaurants and attending significant events such as weddings and holidays leading to further feelings of frustration and isolation [24-26]. Some family members reported looking for opportunities to eat foods that their family member could no longer eat when their family member with dysphagia was not present [26]. Despite the disruptions to family meals and social engagements, the family members in one study reported that they believed the dysphagia did not have a significant impact on their relationship, but had in fact brought them closer together, indicating that family members learn to adapt and adjust to the dysphagia [26].

3.3. Emotional impacts of dysphagia

Numerous emotional impacts of dysphagia on family members have been discussed in the current literature. These emotional impacts have been expressed around a variety of areas. Johansson and Johansson [25] noted that family members of people with dysphagia following stroke or traumatic brain injury expressed concern about their family member's health and well-being, particularly regarding nutrition, weight maintenance, and the need to pay special attention to texture-modified diets. These findings are similar to those found in family members of people with dysphagia following head and neck cancer. Both Patterson et al. [24] and Nund et al. [26] discussed feelings of fear, guilt, frustration, anger, stress, and helplessness over the enforced changes to meal preparation [24,26]. In addition, family members expressed feelings of insecurity, uncertainty, loneliness, and frustration [24-26] when leaving the care of the hospital services. Family members in these studies reported feeling ill-prepared and anxious regarding the increased responsibilities for their family member's food and eating [25-27]. These findings across studies highlight the need for specific interventions for family members to build capacity and provide support in the multiple roles they undertake in caring for their family member with dysphagia [26].

4. Third-party disability in dysphagia

The impact of dysphagia on an individual's family is increasingly being acknowledged as an important consequence of dysphagia [24-26]. The effects of a health condition, such as dysphagia, on the functioning (and disability) of family has been termed "third-party disability" and identified as an area for future work by the WHO [15]. The concept of third-party disability is raised in the situation where the family member may not have a health condition; however, they may experience activity limitations and participation restrictions as a result of their family member's dysphagia.

Although the concept of third-party disability is still under some conceptual debate, to date the ICF has been used successfully to describe the third-party disability of spouses of older people with hearing impairment [36]; close family members of people with aphasia [37]; and more recently, family members of people with dysphagia following head and neck cancer [38].

A model extending the ICF to explain third-party disability has been proposed [36] and an adapted version of this model, specifically relating to dysphagia, is shown in Figure 2. This adapted model demonstrates how the functioning and disability of an individual with dysphagia acts as an environmental factor for the family member, influencing their functioning (and disability).

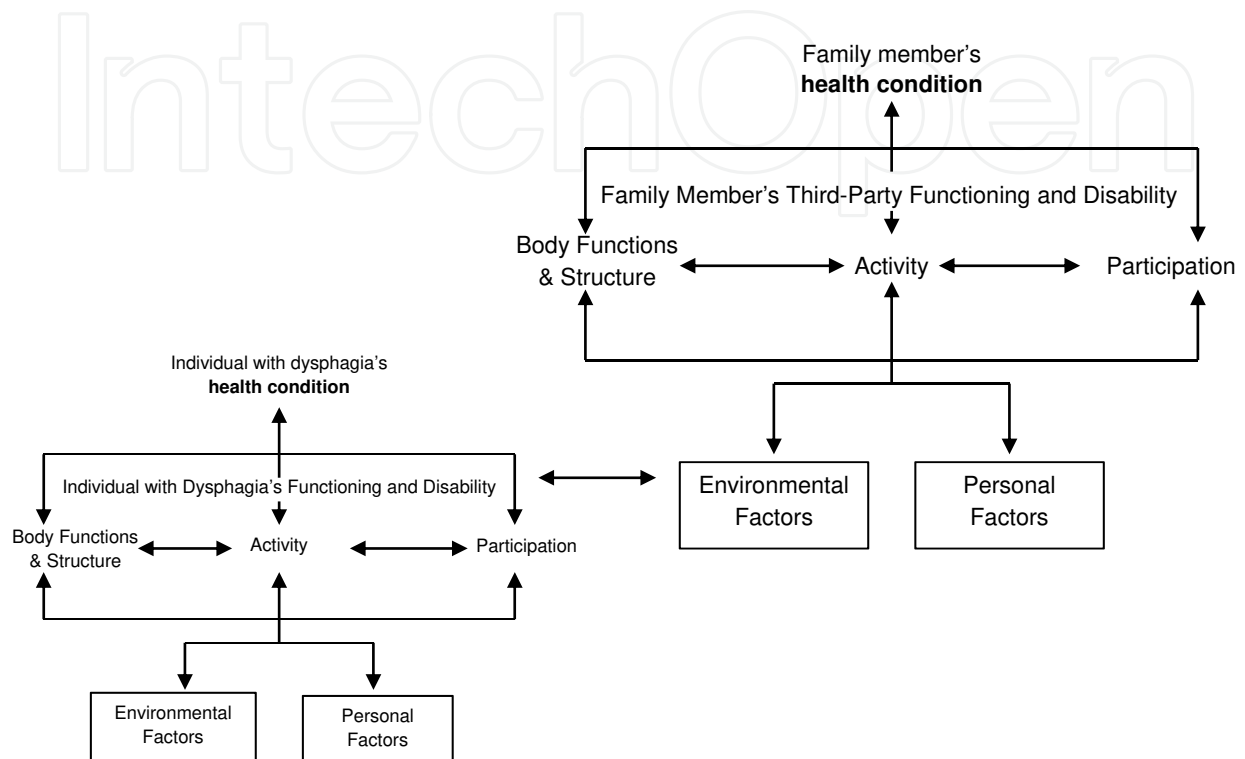


Figure 2. Application of the ICF to family members of people with dysphagia (adapted from Scarinci et al. [36])

In a recent study that mapped family members' experience of dysphagia following head and neck cancer to the ICF, Nund et al. [38] found that the majority of their concerns were linked to the activities and participation component of the ICF (e.g., difficulties or changes to meal preparation were linked to the activities and participation component). It should be noted, however, that these difficulties were generally determined to be performance problems rather than capacity limitations [38]. The difficulties experienced by family members regarding meal preparation were not related to impairments in their body functions, or even in their capacity to prepare a meal. Rather, family members reported experiencing difficulties preparing meals because their family member with dysphagia had specific requirements regarding food and fluids [38].

This finding is consistent with the definition of third-party disability whereby although the family member does not have a health condition, they experience activity limitations and participation restrictions as a result of their partner's health condition (i.e., as a result of their partner's dysphagia) [14]. In this mapping process, it was observed that the most relevant domains of the activities and participation component of the ICF were those of interpersonal interactions and relationships, domestic life, general tasks and demands, learning and

applying knowledge, self-care, major life areas, and community, social and civic life [38]. The number of relevant activity and participation domains highlights the pervasive effects of dysphagia on the life of the carer and demonstrates that food and meals underpin a number of life areas for family members of head and neck cancer survivors with dysphagia. This study confirmed that ICF terminology can be used successfully to describe the multifaceted and complex effects of dysphagia on family members of people treated nonsurgically for head and neck cancer.

5. Strategies used by family members to cope with dysphagia

In response to the pervasive effects of dysphagia, studies reported to date have identified a number of strategies and processes family members adopt to adjust and cope with their family member's dysphagia and the associated impacts on their life [24-26]. A predominant theme across studies is the acceptance of a new normal. That is accepting that meal preparation, mealtimes, and social occasions may never be the same. In order to reach this point, family members across studies noted the need to negotiate changing roles in regards to their family members dysphagia and the need to take on more roles within the household [24-26].

Other strategies reported by family members include maintaining a positive attitude; looking for opportunities to eat foods that their partner could not eat when they were not present; and using trial and error strategies to learn what foods their family member could and could not eat. Each of these strategies and adjustment processes were often made without the support of health professionals and family members across studies have consistently reported the need for further education, training, and support from health professionals to help them adapt and adjust to their family member's dysphagia regardless of etiology or severity of dysphagia [25, 26, 29].

6. Role of family-centered care in dysphagia management

Given the emerging evidence supporting the important role of family members in the provision of informal care for people with dysphagia, and the potential for third-party disability in family members of people with dysphagia, active involvement of family members in all aspects of dysphagia assessment and intervention is clearly indicated. This could be achieved in dysphagia management by shifting from a patient-focused, impairment-based model of intervention, to providing a more holistic, family-centered approach. The Institute for Patient- and Family-Centered Care [39] define family-centered care (FCC) as "... an approach to the planning, delivery, and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients and families." Although traditionally used in pediatrics, FCC can be applied to people of all ages, and used in any health care setting [39, 40].

The term “family-centered care” is sometimes used synonymously with patient-centered care and client-centered care. However, an important distinction between FCC and the other forms of centeredness is that FCC seeks to explicitly assist families in ways that are important to family members [41, 42]. As such, FCC ensures that care is planned around the whole family; and importantly, the entire family is recognized as receivers of care, not just the individual with dysphagia [43, 44]. In the context of third-party disability, FCC is the most relevant type of centeredness in health care because it emphasizes the importance of health care that is mutually beneficial to all [45].

The principles of FCC originated in the field of psychology, and specifically, family-systems theory. According to family-systems theory, the behavior of any individual should be viewed in the context of their family’s social system [46]. This consideration is supported by empirical evidence showing that family relationships affect biological systems, psychological well-being, and health behavior [47]. Therefore, consideration of the contribution of family relationships to health outcomes is an important consideration for any health service. Family-systems theory also supports the notion that family members play an important role in promoting ongoing change and development in an individual’s functioning, and these changes have the potential to affect the entire family unit.

Given FCC has its roots in theories from psychology, there is a body of evidence in the field of psychology supporting the efficacy of involving family members in interventions. The range of psychological disorders for which involvement of family members has been investigated has been diverse, but includes such conditions as obsessive compulsive disorder and problem-gambling [48-57]. This body of research has shown that interventions that include family members are more effective than individual treatment [52, 54]. Research has also demonstrated that the inclusion of family members in intervention increases opportunities for the family to improve their communication [53, 57]. Involvement of family members also allows professionals to obtain a more holistic view of the true impact of the problem as well as the role of family dynamics [56].

Research in pediatric health care has long demonstrated the benefits of FCC for children with a variety of health conditions. A recent systematic review highlighted the benefits for both patients and family members in terms of improvements in the health condition, improved efficiencies and access to health care services, and improved communication between health care professionals and families [58]. In terms of family functioning, a meta-analysis by Dunst et al. [59] also showed improved family behavior and functioning as a result of FCC. More recently, the application of FCC to adult health care services has been discussed in the literature [40], with a number of documented benefits. Studies have shown that active engagement of family members in medical consultations for patients with chronic conditions results in greater patient engagement in decision making [60], improved recall of information [61], improved satisfaction with care and health-related quality of life [62, 63], increased compliance with medical treatments [64], decreased depression rates, and overall better family dynamics for patients and family members [65, 66]. These benefits have been shown to be especially strong for families of patients with physical health conditions due to the physical assistance provided by these family members on a daily basis [67-69]. In the case of dysphagia, it is expected that

due to the chronic nature of this condition and the ongoing supports required by family members in mealtime preparation and assistance, the application of FCC for this population would yield similar benefits.

The Institute for Patient- and Family-Centered Care [39] describes four key components for applying FCC, which could be implemented in dysphagia management: (1) respect and dignity for patients and family members, such that health care professionals listen to and honor the perspectives and choices of patients and family members; (2) the provision of complete and unbiased information to patients and family members such that they can participate effectively in the decision-making process; (3) participation of patients and family members in all aspects of care and decision making; and (4) collaboration with patients and family members in all levels of health care, including policy and program development, implementation and evaluation, facility design, professional education, and in the delivery of care.

In listening and honoring the perspective and choices of people with dysphagia and their family members, clinicians should follow the recommendations outlined by Laidsaar-Powell et al. [70] in order to optimize family member involvement. These include: encouraging, welcoming and involving family members in all aspects of the consultation; and determining the reason for the presence of family members from the perspective of both the patient and family member. Although family members of people with dysphagia may attend consultations with the patient, their role may traditionally be viewed by the health professional as that of “support person” for the individual with dysphagia. However, a recent systematic review of family member involvement in physician consultations highlighted that family members may play a number of roles in supporting patients, ranging from being a memory aide and transcriber to providing emotional support and serving as an advocate and interpreter [70].

A narrow perception of these roles by health professionals may serve to prevent full and active participation in the management plan, with a recent study indicating that health professionals may miss valuable opportunities for engaging family members in designing chronic care management plans, and failing to facilitate participation of family members in consultations [71]. Thus, in order to facilitate FCC in dysphagia management, clinicians should not only be mindful of highlighting helpful behaviors from family members; but also clarifying and agreeing on the role of the family member in the initial stages of the consultation. Laidsaar-Powell et al. [70], however, highlight the importance of respecting patient preferences for family member involvement, ensuring that patients consent to and support the involvement of their family member.

In dysphagia management, the provision of health information that is complete and unbiased is especially important given the health-related quality of life implications of dysphagia [2, 5]. Both people with dysphagia and their family members report the need for more personalized and practical information regarding dysphagia management [13, 26, 28-31]. Johnson [72] further emphasizes the importance of providing complete and unbiased information on a continuous basis. This, of course, is especially important for people with dysphagia who may not understand or have difficulty following recommendations due to associated cognitive impairments [73], and require their family member to take full responsibility for the decision-making process. In dysphagia management, health information must be both family-centered

and holistic in nature, to ensure that the full consequences of dysphagia on the everyday lives of people with dysphagia and their family members are discussed. Previous research has documented the desire of both people with dysphagia and their families to receive more information regarding the potential everyday impacts of dysphagia and how these impacts can be managed [14, 26]. In addition to providing information about the everyday impacts of dysphagia, in order to provide effective FCC, health professionals should also provide information about the role of family members in the management process [74], including issues relating to meal preparation, shopping for textured modified foods, household organization, nutrition, and encouraging their family member with dysphagia to keep eating [26], and importantly, discussion of strategies and resources that may aid them in this role.

Another consideration for clinicians is how this information provided to people with dysphagia and their family members could most effectively inform shared decision making. Shared decision-making is one of the key principles of FCC and involves active participation of both the patient and family in the decision-making process. Kaizer et al. [73] described a shared decision-making model that was used with people with dysphagia and their family members in a rehabilitation hospital setting. Kaizer et al. [73] acknowledged that the use of a family-centered shared decision-making model was important in the management of dysphagia as the success of dysphagia recommendations required considerable cooperation and participation of both people with dysphagia and their family members. Engagement of people with dysphagia and their family in the decision-making process is especially important to ensure that they understand and agree with the recommendations being made. In situations when patients and families feel “forced” to follow a management plan they do not agree with, divisions may develop between family members, hampering positive relations between the patient and family and the health care team [73].

It is clear that in order to promote the best possible outcomes for people with dysphagia, and minimize the third-party disability experienced by family members of people with dysphagia, the provision of more holistic, family-centered approach to dysphagia management is recommended. This chapter has provided some key evidence supporting the use of FCC in other areas of health care, which could readily be applied to services for people with the dysphagia and their families. Some important considerations for the successful implementation of FCC have also been discussed, with concepts from other fields of health care applied to dysphagia rehabilitation.

7. Conclusion

Current research has documented both the medical, psychosocial, and health-related quality of life impacts of dysphagia. In addition, emerging research is also demonstrating the pervasive nature of dysphagia on family members. Though the physiological impacts of dysphagia are generally well recognized and managed, people with dysphagia and their families may also experience significant negative effects on their daily lives including impacts on meal preparation, family dynamics and family mealtimes, social occasions, and psychological

effects. Though clinicians generally recognize the importance of family members, many focus their attention on the individual with dysphagia and therefore the effect of dysphagia on family members is rarely assessed or managed. Providing a more holistic and family-centered approach to dysphagia assessment and management, using a framework such as the ICF, may not only assist the family, but may also result in more positive long-term outcomes for people with dysphagia. In the next decade, further research is required to document the effects of dysphagia on the family and to develop new and innovative treatments for family-centered care in dysphagia management.

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