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Towards Effective Communication: An Exploration of Evidence-Based Strategies for Informal Care Partners Engaged in Difficult Conversations with Individuals with Parkinson's Disease

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Abstract

Communication deficits are common in Parkinson's disease and can compromise the ability for informal care partners to communicate effectively with their partner. This may result in the avoidance of critically important conversations, thus placing strain on the relationship, and can harm the well-being of both parties. The aim of this thesis is to explore evidence-informed communication strategies that can be utilized to assist care partners of individuals with Parkinson's Disease (IWPD) in conducting difficult conversations. Utilizing a scoping review methodology, seven themes emerged from peer-reviewed literature on communication: selecting an appropriate physical environment; conversation preparation; verbal communication skills; non-verbal communication skills; post-conversation actions; care partner character attributes; and communication frameworks tailored for navigating difficult conversations. The results obtained offer practical recommendations that we anticipate will enhance communication skills and the efficacy of care partners in navigating difficult conversations. This review also identifies research gaps and suggests potential next steps forward.

Keywords: Difficult Conversations, Parkinson's Disease, Informal Care Partner, Caregiving, Communication, Scoping Review

Summary for Lay Audience

Care partners play an important role in the lives of individuals with Parkinson's disease (IWPD). Throughout the course of disease progression, a care partner must continue to adapt to the demand and dependence for their care. It is a role that can be very rewarding but challenging to hold. One area of the relationship that may cause challenges for the care partner and care recipient is participating in difficult conversations. In this thesis, one study was conducted to explore the literature for communication strategies that could be used by care partners when they are having difficult conversations.

A scoping review of 4 databases yielded 85 articles that met our inclusion criteria and were included in the review. The results from the literature provided many helpful communication strategies that fall into seven identified themes: i) selecting an appropriate physical environment; ii) conversation preparation; iii) verbal communication skills; iv) non-verbal communication skills; v) post-conversation actions; vi) care partner character attributes; and vii) existing communication frameworks tailored for navigating difficult conversations.

The findings highlight areas of focus and nuances of communication that care partners should be attentive to if they would like to create a suitable opportunity for effective communication with their partner. Additionally, this review of the literature has identified gaps in the current research and suggest potential next steps forward that would better align the communication research to the experience of informal care partners of IWPD to ultimately improve the efficacy of communication for care partners.

Co-Authorship Statement

This thesis contains material intended for a manuscript currently in its final preparation stage. The principal author of the resulting manuscript will be Holmes, J. co-authored by Brinovec, E., Johnson, A.M., Alvarez, L., Hunter, S., and George, C.

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List of Abbreviations

ABCDE	Advance preparation, Build therapeutic environment/ relationship, communicate well, deal with patient & family reactions, Encourage & validate emotions
ADAPT	Ask, Discover, Anticipate ambivalence, Provide info, Track Emotions
BREAKS	Background, Rapport, Explore, Announce, Kindling, Summarize
CPT	Communication Partner Training
DBS	Deep Brain Stimulation
EMPATHY	Emotions, Meeting, Patient's perspective, Adequate language, Truth & Hope, Yes for patient empowerment
GUIDE	Get Ready, Understand, Inform, Demonstrate empathy, Equip
IWPD	Individual with Parkinson's Disease
NURSE	Naming, Understanding, Respecting, Supporting, Exploring
PD	Parkinson's Disease
REMAP	Reframe, Expect Emotions, Map goals, Align, Plan
SEGUE	Set the stage, Elicit Information, Give information, Understand patients perspective, End the encounter
SPIKES	Setting, Perception, Invitation, Knowledge, Emotions, Strategy/Summary

CHAPTER 1

1 Introduction

Parkinson’s disease (PD) stands as the second most prevalent neurodegenerative condition, causing disruptions to the functioning of the nervous system and affecting various areas of the body governed by nerves (Poewe et al., 2017).The symptom profile of PD is diverse, with manifestations encompassing both motor symptoms such as tremor, rigidity, bradykinesia, postural instability, as well as non-motor symptoms including pain, sleep disorders and cognitive changes (Hammarlund et al., 2018;Aarsland et al., 2021; Jankovic, 2008; Johnson et al., 2005; Park & Stacy, 2009). Importantly, the presentation of these symptoms can vary significantly among individuals (Jankovic, 2008; Marras & Lang, 2013; Thenganatt & Jankovic, 2014; Palakurthi & Burugupally, 2019).

The progressive and incurable nature of PD necessitates a fundamental adjustment in the management of day-to-day demands (Hammarlund et al., 2018), encompassing basic and instrumental activities of daily living (Bhatia & Gupta, 2003; Brod et al., 1998). As individuals with PD (IWPD) undergo ongoing functional and cognitive decline (Jankovic & Kapadia, 2001; Aarsland et al., 2009), they frequently require additional assistance to complete daily occupations (Bhatia & Gupta, 2003; Brod et al., 1998).

PD affects more than 1% of individuals aged 65 and older, with its prevalence expected to double by 2030 (Aarsland et al., 2021). Currently, around 100,000 Canadians and 10 million people globally live with PD (Postuma & Anang, 2017). While this condition can manifest in individuals as young as 40, known as “young onset”, it predominantly emerges in those over 60 years of age (De Lau & Breteler, 2006). In Canada, symptoms typically present around the average age of 64.4 years (Wong et al., 2014). Additionally, men are more likely than women to be diagnosed with PD (Dorsey et al., 2018; Willis et al., 2022; Wong et al., 2014). Although PD is progressive, it is seldom fatal. Consequently, IWPD may experience years of gradually declining capabilities, often relying on the support of family and friends as the illness advances (Wong et al., 2014).

The etiology of PD is not completely understood, but it is believed to result from a complex interaction of genetic and environmental factors that influence various essential cellular functions (Kalia & Lang, 2015; National Institute of Neurological Disorders and Stroke, 2015). From a pathophysiological perspective, PD is characterized by the neuronal loss of dopaminergic neurons in the substantia nigra, a critical brainstem structure for controlling movement (Cramb et al., 2023; Jellinger, 2014; Aarsland et al., 2021; Armstrong & Okun, 2020). The substantia nigra produces dopamine, a neurotransmitter that plays a crucial role in relaying messages for planning and controlling body movement (Postuma & Anang, 2017). Motor deficits typically manifest when 50-60% of the dopaminergic neurons in the substantia nigra have already been lost, constraining the potential effectiveness of neuroprotective therapies (Hustad & Aasly, 2020).

A pathological hallmark of PD is the Lewy Body, a structure that can form within nerve cells of the substantia nigra and throughout the brain. These Lewy bodies arise from the abnormal accumulation of α-synuclein, a misfolded protein (Jellinger, 2014; Kalia & Lang, 2015; Armstrong & Okun, 2020; National Institute of Neurological Disorders and Stroke, 2015). These fibril aggregates are linked with the death of dopamine-producing cells, impacting the clinical presentation of the disease (Kalia & Lang, 2015; Armstrong & Okun, 2020).

IWPD exhibit variability in clinical manifestations, the course of the illness, genetic composition, age of onset, progression rate, and treatment response (Jankovic, 2008; Marras & Lang, 2013; Thenganatt & Jankovic, 2014; Palakurthi & Burugupally, 2019). This diversity underscores the heterogeneous nature of PD.

1.1 Motor Symptoms

Parkinson's disease manifests with a combination of motor and non-motor symptoms, contributing to distinctive clinical features that vary among individuals (Jankovic, 2008). The symptomology experienced by an IWPD may also very in intensity, and it is not uncommon for symptoms to initially manifest on one side of the body and subsequently develop contralaterally as the condition advances (Sveinbjornsdottir, 2016; Kouli et al., 2018). There are four cardinal motor characteristics of PD: bradykinesia, rigidity, tremors, and postural instability (balance issues) (Jankovic, 2008; Armstrong & Okun, 2020; Kouli et al., 2018; Rao et al., 2006).

Bradykinesia denotes the slowness of movement and a progressive reduction in the speed of action as the disease advances (Jankovic, 2008; Sveinbjornsdottir, 2016). It involves challenges with planning, carrying out movements, and handling both sequential and concurrent tasks (Berardelli et al., 2001; Jankovic, 2008). Bradykinesia affects all movement and may manifest as increased difficulties performing activities of daily living that involve fine motor movements, including brushing teeth, buttoning up a shirt, or using utensils to prepare food (Jankovic, 2008; Postuma & Anang, 2017). Subsequent presentations of bradykinesia may include slow walking, reduced facial expressivity (hypomimia), drooling secondary to swallowing difficulties, a decrease in amplitude of handwriting (micrographia), and a lack of arm swing while walking (Jankovic, 2008; Postuma & Anang, 2017; Sveinbjornsdottir, 2016).

Rigidity is characterized by an abnormal elevation in muscles tone, evident when joints are moved passively, ensuing in persistent resistance across the entire range of motion (Delwaide, 2001; Baradaran et al., 2013; Anastasopoulos et al., 2009). An individual displaying rigidity may experience the feeling of tightness or lack of flexibility throughout various muscles of the body including the neck, torso, arms, and legs (Endo et al., 2009; Postuma & Anang, 2017).

Tremors represent one of the most prevalent symptoms in PD, affecting up to 75% of patients and often serving as the initial symptom recognized by individuals (Heusinkveld et al., 2018; Abusrair et al., 2022). This rhythmic shaking can pose considerable challenges in daily tasks and, for some, lead to feelings of embarrassment (Fleury et al., 2020). Resting tremors, observed in various areas like the jaw, hands, and feet, are a common subtype (Postuma & Anang, 2017; Jankovic, 2008), with some people exhibiting the distinctive 'pill-rolling' tremor, characterized by circular motion between the thumb and index finger at rest (Sveinbjornsdottir, 2016). Notably, several individuals with PD may experience a reduction in their resting tremor during movement and while asleep (Khalil & Mallik, 2013).

Postural instability represents the final cardinal motor symptom encountered by those living with PD and becomes prominent due to the impairment of postural reflexes, resulting in an incapacity to maintain balance (Jankovic, 2008; Palakurthi & Burugupally, 2019). Individuals may experience challenges with their balance when assuming an upright position or transitioning between different positions, such as moving from seated to standing (Postuma & Anang, 2017). Postural instability in IWPD can manifest as difficulties with gait and increase risk of falling (Sveinbjornsdottir, 2016; Postuma & Anang, 2017).

1.2 Non-Motor Symptoms

Parkinson's disease, often primarily perceived as a condition affecting motor function, extends it impact to a broader spectrum of non-motor symptoms. This broader influence is not only known to precede motor manifestations, but also amplifies the disease burden for the individual and their care partner (Mosley et al., 2017; Goldman & Postuma, 2014; Marinus et al., 2018; Hiseman & Fackrell, 2017). As a multisystem disease, the induction of neurochemical and neuroanatomical changes occurring with progression has been observed to cause impairment in cognition, neuropsychiatric symptoms, autonomic and sensory dysfunction, and sleep disturbances (Park & Stacy, 2009; Goldman & Postuma, 2014).

IWPD may exhibit cognitive impairments resulting in increased difficulty associated with memory, executive functioning, verbal fluency, slowed information processioning (bradyphrenia), and variations in attention (Park & Stacy, 2009; Mosley et al., 2017). Deficits in executive functioning can create challenges in carrying out everyday activities such as medication management, as impairments in goal-directed behaviours may reduce skills such as attention and planning required for task completion (Mosley et al., 2017). Several neurological disorders frequently coexist with PD, with dementia being the most prominent. It is estimated that roughly 75% of individuals who live with PD for more than 10 years will develop dementia, subsequently diminishing cognition (Aarsland &

Kurz, 2010; Park & Stacy, 2009). Moreover, IWPD may commonly present with neuropsychiatric symptoms, including depression, anxiety, apathy, and psychosis which have implications on one's quality of life and daily functioning (Aarsland et al., 2009). These manifestations can evoke feelings of sadness, irritability, and worry, as well as lead to diminished motivation, flattened affect, and a sense of indifference (Martínez-Horta et al., 2014; Pluck & Brown, 2002; Postuma & Anang, 2017). The convergence of these diverse non-motor symptoms not only complicates disease management, but the escalating burden of caregiving can evoke emotional frustration, helplessness, and sadness in care partners (Postuma & Anang, 2017; Aamodt et al., 2023).

1.3 Management of Parkinson's Disease

PD is a complex neurodegenerative condition, and while there is no cure, various management strategies aim to manage symptoms and enhance quality of life for individuals affected. The most common treatments for PD are pharmacological interventions that are primarily centered around dopamine (Armstrong & Okun, 2020). Levodopa, a synthetic form of dopamine, stands out as one of the most effective options for addressing motor symptoms, particularly bradykinesia and rigidity (Postuma & Anang, 2017; Jankovic & Aguilar, 2008). In select cases, this medication may also target tremors (Postuma & Anang, 2017). However, prolonged use of Levodopa can lead to motor fluctuations, such as wearing-off and dyskinesias. In many cases, a combination of medications, including dopamine agonists (which mimic dopamine in the brain), and MAO-B inhibitors (which impede the breakdown of dopamine in the body), provide alternative options (Emamzadeh & Surguchov, 2018). However, these classes of pharmacological interventions are associated with less substantial symptom relief compared to Levodopa (Armstrong & Okun, 2020; Jankovic & Aguilar, 2008).

In addition to pharmacological interventions, select IWPD may benefit from a neurosurgical approach to management. Deep brain stimulation (DBS) is a treatment option that may be suitable for those who experience medically intractable, motor fluctuations, and/or dyskinesia that are not effectively managed by medication (Abusrair et al., 2022; Armstrong & Okun, 2020; Pouratian et al., 2012; Pollak et al., 2013;). DBS involves the administration of high-frequency electrical impulses via transcranial electrodes implanted into the brain structures involved in controlling movement, including the subthalamic nucleus and global pallidus interna (Jankovic & Aguilar, 2008; Limousin & Martinez-Torres, 2008; Abusrair et al., 2022; Groiss et al., 2009). Although this is a clinical practice that has been utilized for decades and has demonstrated symptomatic reductions for IWPD, the therapeutic mechanism of DBS is not definitively understood (Abusrair et al., 2022; Lozano et al., 2019; Van den Boom et al., 2023). However, there are various theories that have been presented including the “inhibition hypothesis” which suggests DBS inhibits neural tissue around the electrode, and recently an adapted iteration to this theory that postulates DBS acts as an “information lesion” that causes disruption at an informational level (Van den Boom et al., 2023; Lozano et al., 2019).

Non-motor symptoms of PD are commonly managed by employing treatments that are used in the broader population unaffected by PD (Armstrong & Okun, 2020). This may include the prescription of selective serotonin reuptake inhibitors (SSRIs) for depression, benzodiazepines for anxiety, or various anti-psychotic medications to treat psychosis. Therefore, the heterogenous nature of PD calls for personalized care and the careful selection of treatments aiming for maximized efficacy while reducing the likelihood of adverse events.

Regardless, of the treatment used, the progressive nature of PD over time results in diminished independence and often necessitates assistance from care partners. The involvement and support of care partners becomes crucial in navigating the challenges posed by the evolving nature of the disease.

1.4 Informal Care Partners

The insidious onset of disability resulting from PD heightens the reliance on caregiving, a responsibility primarily shouldered by informal care partners, such as a spouse and/or family members (Hulshoff et al., 2021; Bhimani, 2014). Traditionally, the terms "care partner" and "caregiver" have been used interchangeably in the literature. However, recent perspectives from those with lived experience suggest a nuanced difference (Bennett et al., 2017). In the early stages of the disease, one may function more as a care partner, indicating a collaborative partnership between the care partner and the care recipient, who can actively participate in day-to-day activities. As the disease progresses and the care recipient loses much of their independence, the term "caregiver" more appropriately describes the increased level of support provided by the individual delivering care. In this thesis, the term "care partner" will be used to denote the person assuming the primary caregiving duties for the IWPD. This choice emphasizes the reality that the disease process impacts both the care partner and the care recipient (Bhimani, 2014). Informal care partners play a pivotal role in the comprehensive care of IWPD, encompassing the essential requirements of social, physical, and psychological support over an extended period (Goy et al., 2008).

Throughout the course of disease progression, the assumed responsibilities of care partners evolve as the demand and dependence for their care typically increase in the later stages (Mosley et al., 2017). Primary duties may include coordinating care, accompanying their loved one to appointments, advocating for services, managing medications, monitoring for falls, taking on additional household responsibilities, and increasingly assisting with daily activities as the disease progresses (Mosley et al., 2017; Geerlings et al., 2023).

Moreover, informal care partners play a crucial role in preventing or at least slowing down the emergence of PD complications that might warrant the institutionalization of their loved one (Geerlings et al., 2023). Care partners of IWPD are an important link that allows for the care recipient to remain in the community, and reduce the risk of institutionalization (Grün et al., 2016; Rongve et al., 2014). Additionally, informal care partners in Canada provide an immense amount of unpaid care for family members in need, add significant value to our economy, and play a crucial role in maintaining the well-being of Canadians (Hollander et al., 2009; Wray et al., 2023). As of 2018, it is estimated that 1 in 4 Canadians are informal care partners (Statistics Canada, 2022), a number assumed to rise as the population continues to age. The annual economic value of unpaid caregiving in Canada has been valued to be greater than 25 billion dollars (Hollander et al., 2009; Health Council of Canada, 2012), thus highlighting the invaluable contribution informal caregivers provide to the economy, health care system and society (Mosley et al., 2017; Hollander et al., 2009).

Taking on the role of a care partner is a highly individualized experience, with some people finding it incredibly fulfilling, while others encounter significant challenges. Pristavec (2019) has highlighted that the benefits derived from caregiving are diverse, encompassing interpersonal advantages such as building close relationships and feeling companionship and appreciation. Emotional benefits include satisfaction in knowing that a loved one is well cared for, a sense of accomplishment, fulfillment, and personal growth (Quinn et al., 2012). Additionally, caregiving can result in behavioral and cognitive benefits, leading to the acquisition of new skills, competencies, and abilities (Carbonneau et al., 2010).

Despite the positive outcomes reported by informal care partners, much of the existing literature tends to emphasize the negative aspects (Schwartz et al., 2020). In particular, significant attention has been directed towards the lived experiences of care partners in relation to the burden they may bear (Geerlings et al., 2023).Caregiver burden, a specific type of stress stemming from the demands of the caregiving role, is defined as the degree to which care partners perceive the impact of providing care on various aspects of their well-being, including emotional or physical health, financial status, and spiritual functioning (Zarit et al., 1986). Caregiver burden has been known to place physical and psychological stress on care partners, resulting in increased medical and psychiatric co-morbidities (Aamodt et al., 2023).

Previous research has outlined predictors and contributors to the perception of burden, many of which can be identified as characteristics relating to the care recipient and care partner. Factors attributed to the IWPD included the presence of progressive motor symptoms that impair functioning (Aamodt et al., 2023). Among the motor symptoms, akinesia, and rigidity where more highly correlated than tremors in contributing to caregiver burden (Torny et al., 2018; Moretti et al., 2017). Additionally, research conducted by Abeynayake & Tanner (2020), suggests that care partners of individuals with “off” periods, a time when symptoms can worsen between doses of pharmaceutical intervention, saw an increase in economic burden due to more missed work and lower productivity at work.

Non-motor symptoms, specifically neuropsychiatric symptoms (depression, apathy, hallucinations, delusions, psychosis, agitation, aggression) and sleep disturbances, are strong predictors of care partner health-related quality of life and can negatively impact care partner well-being (Aamodt et al., 2023). As neurodegeneration continues, the increasing need for support, physical dependence, and reduced ability to carry out activities of daily living, can all be attributed to higher rates of caregiver burden (Jensen et al., 2021; Lo Monaco et al., 2021). Subsequently, data has shown that care partners who provide care to males with PD have a worse quality of life (Henry et al., 2020), a gender difference that has been surmised to occur due to more disabling symptoms present among men including dementia, psychosis, and falls (Iwaki et al., 2021).

Research has also shown that PD care partners have presented with higher rates of anxiety and depression compared to controls, thus exacerbating levels of perceived burden (Vescovelli & Ruini, 2022; Macchi et al., 2020; Aamodt et al., 2023). Care partner stress also appears to be amplified when a lack of reciprocal understanding is present from family and one’s extended social circle (Aamodt et al., 2023). Moreover, Wressle and colleagues (2007) deduce that care partner fatigue and a lack of understanding from friends contributed to reduced socialization of the care partner, lending to the experience of social isolation which can be a consequence of caring for people with chronic disease (Theed et al., 2017). Therefore, the interpretation of insufficient levels of social support is a characteristic that has been identified in increased levels of caregiver burden (Geerlings et al., 2023).

The impacts resulting from caregiver burden are far-reaching, multi-dimensional, and unique to each person. The challenges that arise from shouldering the responsibilities associated with caring for someone whose dependence on your support heightens over time, can have repercussions on physical and emotional health (Theed et al., 2017). This situation may lead to loss and disruption of relationships, dashed hopes, disruptions to future plans and can herby leave care partners to feel isolated while undergoing a shift in their previously established identity (Bhimani, 2014; Aamodt et al., 2023; Vatter et al., 2018; Geerlings et al., 2023). The engrossing nature of the care partner role can lead to the depersonalization of oneself. The continuous demands of this role can leave care partners feeling as though they are living a life "for," rather than "with" their partner, herby acting as an expansion of the IWPD. The burden of care can create a breeding ground for self-neglect, and estrangement from individuality, components that have become synonymous with being a care partner to an IWPD (Bhasin & Bharadwaj, 2021).

Given the intimate nature of the caregiving role, the significance of effective communication cannot be overstated. Communication is a vital function that defines humans as individuals, it is foundational to interpersonal relationships and the inability to communicate can have devastating effects (Smith & Caplan, 2018). Communication impairments are quite common for IWPD and are present in up to 90% of cases (Miller et al., 2007; Smith & Caplan, 2018). Due to the disordered motor system and cognitive impacts, there are a variety of communication deficits one may experience that can manifest as language production and comprehension difficulties (Holtgraves & Cadle, 2016).

Hypokinetic dysarthria, characterized by a monotone, breathy voice, and articulation problems (Atalar et al., 2023), and hypophonia, reduced speech intensity, are both speech production impairments associated with PD (Saldert & Bauer, 2017). In a study conducted by Schalling and colleagues (2017), the most dominant communication symptom experienced by 71% of 188 respondents with PD was a weak voice, followed up by difficulties in word retrieval, reflecting a reduction in cognitive function that hinders effective communication. The impairments that manifest from speech-related difficulties have a profound impact on IWPD. This could give rise to feelings of embarrassment, limitations in communication involvement, implications for both work and family life, and social withdrawal, eventually diminishing their quality of life as active social beings (Schalling et al, 2017; Miller et al., 2006; Kavya et al., 2022). Additionally, syntactically complex sentences, impaired emotion recognition, and difficulties identifying the pragmatic meanings in speech/language, are all comprehension deficiencies that may be present (Holtgraves & Cadle, 2016). Therefore, having a compromised ability to effectively communicate with their partner is particularly troublesome for care partners (UNECE, 2019), especially at times when care partners find it necessary to broach conversation that are perceived as being difficult in nature.

1.5 Difficult Conversations

Browning, Meyer, Truog, & Solomon, (2007) describe “difficult conversations” as emotionally charged discussions characterized by uncertainty. A unique element of this form of communication is that the measured “difficulty” of a conversation is a subjective concept that can vary based on the individual in question (Darling & Soehner, 2016). The resistance to communication may occur whenever expressing thoughts becomes challenging, emotions intensify, there is a potential for relational harm or when the discussion holds considerable significance (Darling & Soehner, 2016). Although difficult conversations are a routine part of life, they continue to evoke feelings of anxiety and discomfort for many people (Levine & Cohen, 2018). Consequently, individuals may choose a path of dishonesty or an avoidance of the challenging communication all together (Levine & Cohen, 2018; Priftanji et al., 2020). There is a myriad of situations that may call for one’s involvement in a difficult conversation, ranging from a professional setting where discussing a colleague's underperformance may be necessary, to the personal aspects of an individual's life where they choose to express their emotions to a family member (Levine & Cohen, 2018; Darling & Soehner, 2016). Regardless of the context, these challenging conversations are a means to solve problems and sustain relationships (Priftanji et al., 2020).

While the topic of holding difficult conversations has been framed across many contexts (Levine et al., 2020; Bradley & Campbell, 2016), the strategies put forth to aid individuals in navigating such conversations are overwhelmingly targeted towards health care professionals, operating in a clinical setting, and often employed with the task of “breaking bad news” by disclosing a patient’s medical information. In a health care setting, difficult conversations typically occur between health care professionals, patients, and families. Topics of discussion that are often characterized as being “difficult” include diagnosis of disease, poor prognoses, limitation of current treatments, end-of-life decision making for loved ones, and death (Keating et al., 2013; Davidson, 2007; Planalp & Trost, 2008). Moreover, difficult conversations may cause discomfort to the communicator or recipient (Levine et al., 2020).

For care partners of IWPD, the inevitable limitation on occupations due to disease progression often warrants the need for difficult conversations. For instance, a care partner might need to discuss the cessation of driving for the IWPD as the occupation may become dangerous in more severe forms of PD (Singh et al., 2007), and motor and non-motor impairments can affect one's fitness to drive (Classen, 2014). Such conversations, while potentially difficult, are crucial in maintaining the protection and safety of the IWPD and those directly impacted on the road by the operation of the motor vehicle.

However, studies reveal that care partners and family members frequently sidestep these difficult conversations entirely (Schulz et al., 2017; Tang, 2019). Findings from research conducted by Tang (2019) suggest that family care partners in China have trouble participating in truth disclosure with their elderly family member. Out of fear they will cause worry and/or discouragement in their loved one who unknowingly has been diagnosed with cancer, it was common practice for family care partners to refrain from having a difficult conversation regarding the disclosure of diagnosis to them. Additionally, Schulz and colleagues (2017) highlight that even within families that experience on-going communication and supportive family relationships, difficult conversations including those that touch upon one's mortality can be subjected to barriers that stifle communication. Powerful emotions expressed by a care recipient was an example of a barrier that halted communication between a dying mother and her daughter when discussing plans for end of life. This avoidance in conversation not only impacts the dynamics of the dyad but can also affect the overall health and well-being of both parties involved (Fried et al., 2005). Fried and colleagues (2005) revealed a correlation between care partners increased desired for communication and their perceived burden, underscoring the potential implications of unmet communication needs for the care partner.

The communication challenges faced by IWPD may require care partners to employ specific strategies to facilitate and maintain effective communication during difficult conversations. To date, there remains a paucity of literature that aids in the navigation of difficult conversations from the experience of a care partner operating within the confines of the informal caregiver-care recipient dyad. Finding appropriate ways to effectively support and enhance communication between the dyad can have positive benefits for both parties including its effect on providing improved quality care for the IWPD and strengthening the dyadic relationship (Fried et al., 2005).

1.6 Study Aim

The aim of this thesis is to identify evidence-informed communication strategies drawn from the existing literature, that care partners of IWPD may utilize to better prepare themselves to undertake difficult conversations. The overarching goal is to empower informal care partners with a toolkit of communication strategies, equipping them with the necessary knowledge to help navigate difficult conversations with sensitivity and efficacy. Through evidence-informed insights and practical recommendations, this thesis endeavours to play a meaningful role in enhancing the communication skills and, consequently, the caregiving experiences of informal care partners in the context of navigating difficult conversations.

CHAPTER 2

2 Methods

2.1 Scoping Review Methodology

A scoping review is a type of evidence synthesis that aims to identify and map pertinent literature to capture the comprehensive scope and depth of a field (Arksey & O’Malley, 2005; Levac et al., 2010; Munn et al., 2018; Peters et al., 2021). The purpose of a scoping review can be diverse, such as identifying the nature of evidence in a specific field, examining current research practices on a particular topic, serving as a preliminary step to a systematic review, or identifying research gaps in existing literature (Arksey & O'Malley, 2005; Munn et al., 2018). A scoping review was chosen as the most suitable approach to comprehensively explore and encompass the breadth of existing literature.

Scoping review studies set themselves apart from systematic reviews in that there is no mandatory requirement to assess the methodological quality or potential bias associated with a study. This is because they do not aim to provide judgment on the strength of evidence concerning specific interventions or policies. (Arksey & O’malley, 2005; Levac et al., 2010; Rumrill et al., 2010; Peters et al., 2021). Moreover, the methods employed to identify relevant literature in a scoping review are highlighted as an iterative process that generally leans towards using a broad research question with the aim of capturing all relevant literature, irrespective of the study design. In contrast, a systematic review usually follows a highly focused research question and establishes its ridged inclusion and exclusion criteria at the beginning of the research (Arksey & O’malley, 2005; Armstrong et al., 2011).

The methods for this scoping review are based on the recommendations outlined in the framework by Arksey and O’Malley (2005), and further developed by Levac, Colquhoun, and O’Brien (2010). Collectively, these guidelines suggest the execution of the following six stages: (1) identify the research question; (2) identify relevant studies; (3) study selection; (4) charting of the data; (5) collation, summary, and reporting of the results; and (6) consultation.

2.2 Research Question

The primary research question that guided this inquiry was identified as follows: *What is known from existing published literature about communication strategies that may be used to assist care partners in navigating difficult conversations?*

2.3 Search Strategy & Eligibility Criteria

The following search strategy was developed through consultation and collaboration with an experienced research librarian from Western University. Articles that aligned with the research objective were identified through a systematic search of the following electronic databases: Ovid Medline, CINAHL, Scopus, and PsycINFO. The search was conducted in June of 2022, a combination of subject headings and keywords were used to represent the main concepts of **"difficult/ challenging conversations"**, **"informal care givers"**, and **"communication."** Table 1 presents a detailed overview of the search strategies employed for each database.

Table 1. Search Strategies[1]

CINAHL	Medline (OVID)	PsychInfo (OVID)	Scopus
1. (hard OR difficult OR challeng* OR uncomfortable OR unpleasant) N3 conversation* 2. Caregivers OR (informal or spous* or family) N3 caregiv* OR (carer* OR caregiv* OR spous* OR "significant other" OR partner*) 3. (break* OR deliver* OR giv* OR convey* OR communicat*) N3 "bad news" 4. S1 OR S3 5. S2 AND S4	1. ((((hard or difficult or challeng* or uncomfortable or unpleasant) adj3 conversation*) or (break* or deliver* or giv* or convey* or communicat*)) adj3 bad news).tw. 2. (((Caregivers or (informal or spous* or family)) adj3 caregiv*) or (carer* or caregiv* or spous* or "significant other" or partner*)).tw. 3. difficult conversation.tw. 4.non verbal communications.tw. or Nonverbal Communication/ 5. Caregivers/ 6. 1 or 3 or 4 7. 2 or 5 8. 6 and 7 9. limit 8 to (English language and humans)	1. ((((hard or difficult or challeng* or uncomfortable or unpleasant) adj3 conversation*) or (break* or deliver* or giv* or convey* or communicat*)) adj3 bad news).tw. 2. (((Caregivers or (informal or spous* or family)) adj3 caregiv*) or (carer* or caregiv* or spous* or "significant other" or partner*)).tw. 3. difficult conversation.tw. 4. non verbal communications.tw. or Nonverbal Communication/ 5. Caregivers/ 6. 1 or 3 or 4 7. 2 or 5 8. 6 and 7 9. limit 8 to (human and English language)	1. TITLE-ABS-KEY (((caregivers OR (informal OR spous* OR family)) W/3 caregiv*)OR (carer* OR caregiv* OR spous* OR "significant other" OR partner*)) 689,235 2. TITLE-ABS-KEY (((hard OR difficult OR challang* OR uncomfortable OR unpleasant) W/3 conversation*) OR ((break* OR deliver* OR giv* OR communicat*) W/3 bad AND news)) 3,491 3. (TITLE-ABS KEY (((caregivers OR (informal OR spous* OR family)) W/3 caregiv*) OR (carer* OR caregiv* OR spous* OR "significant other" OR partner*))) AND (TITLE-ABS-KEY (((hard OR difficult OR challang* OR uncomfortable OR unpleasant) W/3 conversation*) OR ((

			break* OR deliver* OR giv* OR communicat*) W/3 bad AND news))) 293
N3 and adj3 are proximity indicators to increase the sensitivity of the search to locate words that are within a certain number of words from each other.			

While there were no restrictions placed on date of publication, English-language articles published exclusively in peer-reviewed journals were considered. This decision was made to ensure the highest level of validity, rigor, and quality in the sources used to inform our research. Grey literature, such as dissertations/theses, reviews, and book chapters, were deliberately omitted from the review (see table 2 for selection criteria).

Table 2. Selection Criteria

Inclusion Criteria	Exclusion Criteria
• Published in a peer-reviewed journal. • Published in the English language. • Articles that clearly and effectively present information on the nature of difficult conversations • Provides techniques, models, and/or advice on how to conduct difficult conversations that is applicable to informal care partners.	• Non-peer reviewed publications. • Grey literature. • Non-English language publications. • Inaccessible articles behind a paywall.

In the selection criteria, priority was given to articles that provided clear and comprehensive insights into the nature of difficult conversations. Specifically, literature was sought that elaborated on the intricacies of such conversations, and offered techniques, models, or guidance on how to navigate and conduct them successfully. The goal was to curate a collection of peer-reviewed articles that provided both a comprehensive understanding of the topic and actionable strategies for effective communication that could be utilized by informal care partners of IWPD.

2.4 Article Screening & Selection

Citations obtained from the systematic review were uploaded to Covidence, a systematic review management software platform designed to streamline the review process. To ensure the accuracy and precision of the review, both automatic and manual duplicate removal procedures were implemented. Through these efforts, duplicates were efficiently identified and eliminated, ensuring that all remaining citations were unique.

Throughout the review process, reviewers were reminded to keep the following overarching research question at the forefront of their evaluation: Does this source clearly and effectively present information on the nature of difficult conversations and/or techniques, models, or advice for how to successfully conduct them?

To ensure consistent application of the inclusion/exclusion criteria, before commencing the title and abstract screening, a member of the research team and I independently assessed 15 articles and compared decisions. Once a general agreement on how to apply the criteria was achieved, the process of selecting articles for inclusion during the title and abstract screening phase was carried out, with articles included based on consensus. Any discrepancies that arose were resolved through discussion, and in cases where a consensus could not be reached, a 3rd independent reviewer (the thesis supervisor) was consulted. Articles that successfully passed the title and abstract screening then underwent a full-text review, conducted by the same two team members who completed title and abstract screening. Articles that failed to meet the inclusion criteria were excluded.

2.5 Data Extraction

A member of the research team and I worked collaboratively to iteratively design a data extraction table using Microsoft Excel. To ensure the consistency of data extraction, each of us independently reviewed five full-length articles and compared results before commencing this step to confirm similar data attributes were being extracted. Following the recommendations presented by Arksey & O'Malley (2005), information was extracted on specific study characteristics. This approach provided a structured method to ensure that the data collected was both relevant and organized for analysis. The following study characteristics were gathered to offer an overview of each study: (1) publication type (2) author (3) year of publication (4) title of publication (5) study methodology (6) primary objective (7) demographic characteristics of participants (e.g., age, sex) (8) type of participants (e.g., caregiver, health care professional, patient diagnosis etc.) (9) topic of difficult conversation (10) participants involved in the difficult conversation (11) communication strategies presented.

2.6 Collating and Summarizing the Data

The process of collating and summarizing the extracted data was conducted collaboratively by me and my thesis supervisor. This phase involved the systematic analysis and iterative organization of the collected information to identify overarching trends, concepts, and gaps in the literature.

2.7 Consultation

While we did not consult key stakeholders, it's worth noting that this process will be undertaken in a subsequent Delphi study that is currently ongoing. In this Delphi study, consensus will be built with feedback from care partners and healthcare professionals. This iterative process allows for a more comprehensive and inclusive approach to synthesizing the gathered data and refining the findings, ultimately contributing to the overall rigor of the research.

CHAPTER 3

3 Results

The primary objective of this scoping review was to systematically identify evidence-informed communication strategies that informal care partners of IWPD could adopt when engaging in difficult conversations. A rigorous search was conducted across four databases: CINAHL, Medline, PsychInfo, and Scopus, yielding a total of 1,096 citations. After the removal of duplicates, 888 references remained for title and abstract screening. Further screening identified that 690 articles did not meet the predefined inclusion criteria. The remaining 198 articles were evaluated through an in-depth review of their full-text publications, resulting in the exclusion of 113 articles. Among the excluded articles, 55 were omitted for failing to present information or advice on conducting difficult conversations relevant to informal care partners, 19 lacked peer review status, 15 were not written in the English language, 13 remained inaccessible behind paywalls, and 8 articles proved elusive despite collaborative efforts with a Western University Research librarian. Additionally, 3 author requests went unfulfilled, contributing to the overall exclusion count. Therefore, in total 85 articles were included for detailed extraction and analysis. Total counts of references identified, screened, selected, excluded, and included are presented in a PRISMA flow diagram (Figure 1).

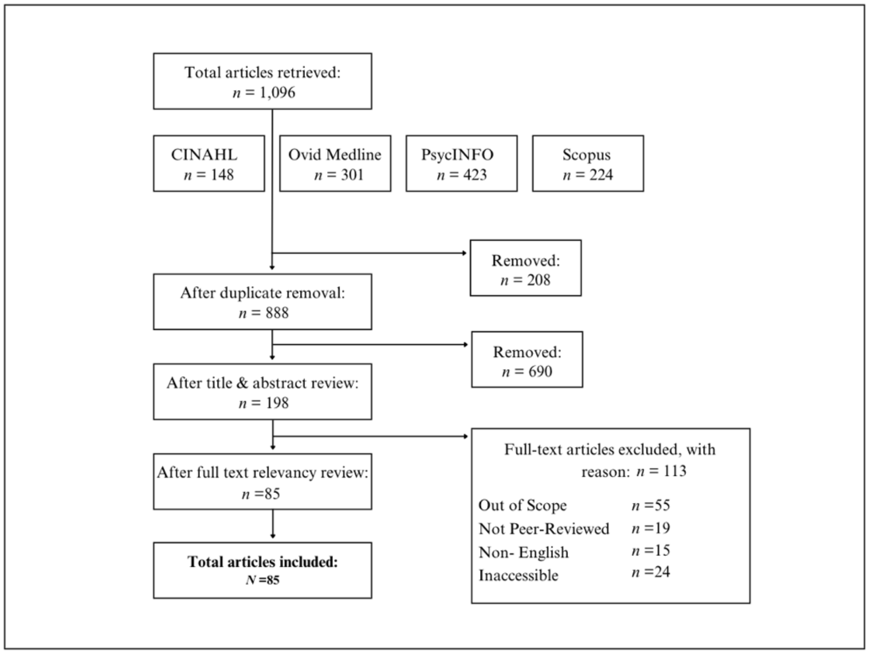

Figure 1. PRISMA flow diagram

3.1 Characteristics of Included Studies

The publication date of articles spanned from 1981 to 2022 and revealed a discernible upward trend in research output over the last decade (Figure 2). Notably, the year 2017 stood out with the highest number of identified publications, totaling 9 articles. Participants identified in the literature as contributors to conversations,, particularly difficult in nature, encompassed a varied spectrum(Table 3). Among the 85included articles, patients with diverse health conditions were present in 71 articles, physicians were mentioned in 61 articles, and nurses were included in a total of 22 articles. Additionally, four articles used the terms “health care providers,” “clinicians,” “health care professionals,” or “counsellor,” but did not specifically identify the individual’s occupational credentials (i.e. physician, nurse, psychologist etc.). A total of 53 articles highlighted the presence of informal caregivers/family in these conversations, represented by parents, adult children, grandchildren, sibling, spouse, daughter in-law, and/or close friend. Five articles singled out the sole use of couples in their research. Social workers were mentioned in five articles as well. Finally, a range of participants emerged in a limited number of studies, encompassing professional students (nursing, medicine, pharmacy), physiotherapists, speech and language therapists, occupational therapists,

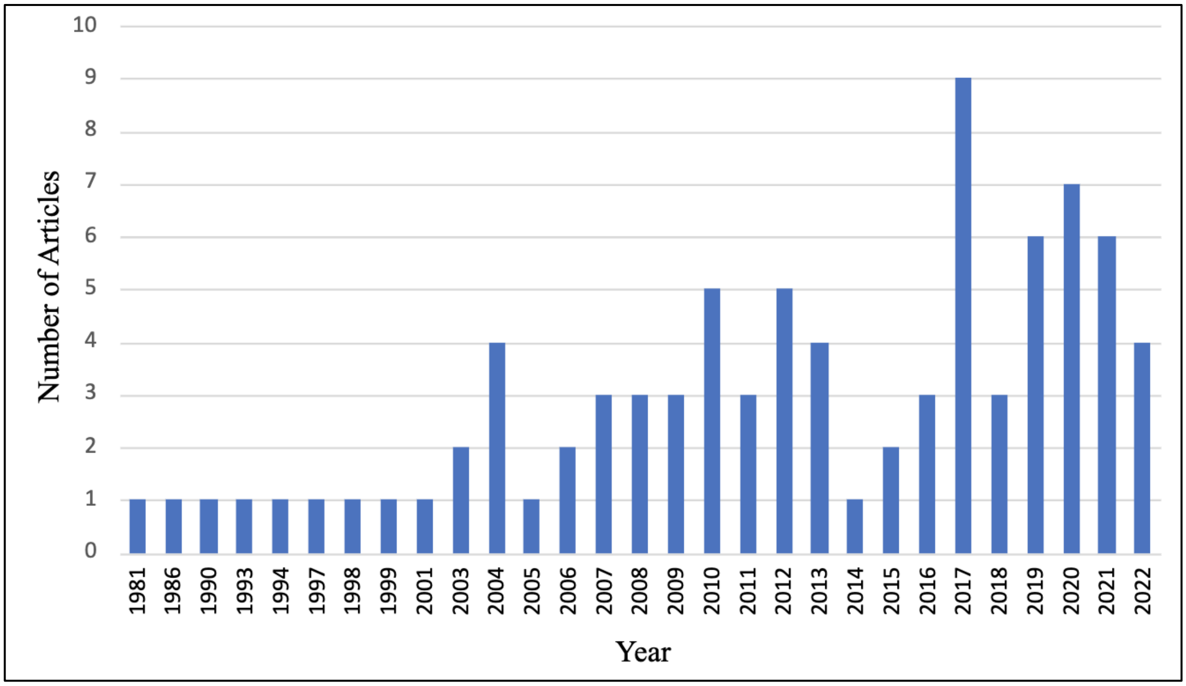

Figure 2. Publication Year of Included Articles

formal caregivers, psychologist/neuropsychologist, patient care navigator, hospice volunteer, child welfare worker, and university students. Table 3 provides a detailed breakdown categorization of individuals represented in the included articles.

Table 3. Type of Communication Partners Present in the Literature

Communication Partners	*Article Number*
Patients	1,3,4,5,6,7,9,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,26,27,29,30,31,32,33,36,37,38,39,41,42,43,44,45,46,47,49,50,51,53,54,55,56,58,59,60,62,63,64,65,66,67,68,69,70,71,72,73,75,76,77,78,79,81,82,84,85
Physicians	1,2,3,4,5,7,10,14,15,16,17,18,19,20,22,23,24,25,26,27,29,31,32,33,34,36,37,38,39,41,42,43,44,45,47,49,50,51,54,56,57,58,59,60,61,62,63,64,66,67,68,71,72,73,75,76,77,78,79,82,84
Health Care Providers (not specified)	11,21,48,53
Nurse	6,9,13,14,20,24,25,26,32,34,41,45,49,54,66,67,68,69,70,71,73,78
Informal Caregiver/Family	2,3,5,6,9,10,13,14,15,16,18,19,20,21,22,23,26,27,28,29,30,31,32,34,36,38,42,44,45,46,47,53,54,56,57,58,61,62,63,65,68,69,70,71,72,73,74,75,76,77,78,79,84
Couples/Spouses	8,30,40,52,80
Social Worker	19,25,49,66,71
Professional Student	19,43
Physiotherapist	19,49
Formal Caregiver	81,85
Occupational Therapist	49
Psychologist/Neuropsychologist	49
Patient Care Navigator	55
Hospice Volunteer	65
Child Welfare Worker	74
University Student	28

A variety of medical conditions or diseases were represented across the difficult conversation literature. Cancer was highlighted as the most prevalent, with references to cancer patients appearing in 34 articles. The second most prominent disease/conditions were neurological in nature, encompassing 20 articles. Motor neuron disease (as known as Amyotrophic Lateral Sclerosis) and Dementia/Alzheimer’s patients were discussed in

9 articles. Other notable neurological conditions included Parkinson’s disease, multiple sclerosis, muscular dystrophy, stroke, myasthenia gravis, Huntington disease, traumatic brain injury, spinal cord injury, brain hemorrhage, and muscle disease (peripheral myopathy). Eight articles included patients with obstetric-gynecological conditions (i.e.. pregnancy abnormalities, fetal life-limiting illness, miscarriage, or ectopic pregnancy) and six articles discussed communication with patients who have cardiovascular disease (ie. heart failure). Three articles included communication with patients diagnosed with respiratory disease/illness, two articles pertained to challenging conversations regarding the dying or death of a child. In two articles, the focus was on people with intellectual disabilities. Other diseases or conditions that were minimally represented in the literature included aphasia, diabetes, dermatological conditions, orthopedic injury, gastroparesis, human immunodeficiency virus, Crohn’s disease, psychiatric conditions, dermatological conditions, and chronic kidney disease. Table 4 provides a detailed breakdown of the medical conditions and diseases represented in the literature.

Table 4. Disease & Conditions Represented in the Literature

Disease/Condition	*Article Number*
Aphasia	12
Dermatological Condition	13
Death/Dying Children	32,34
Diabetes	19
Cancer	4,5,6,17,19,23,26,29,30,31,33,36,37,38,41,45,53, 54,55,58,59,60,65,66,69,70,71,72,73,77,78,79,82,84
Cardiopulmonary Disease	58
Cardiovascular Disease	5,19,21,26,68,78
Renal Disease	1,58
Crohn’s Disease/ Abdominal Problems	19,78
Gastroparesis	19
Human Immunodeficiency Virus	11
Intellectual Disability	76,77
Orthopedic Disease/Injury	19,44
Pregnancy Abnormalities/Obstetrics-Gynecology Conditions/Fetal Life Limiting Illness	1,15,18,33,38,50,57,64

Psychiatric Condition	20,25
Motor Neuron Disease	3,10,14,16,42,47,52,56,70
Dementia & Alzheimer’s Disease	10,22,27,49,63,65,70,80,81
Parkinson’s Disease	10,19,65,70
Multiple Sclerosis	10,70
Muscular Dystrophy	10, 14,70
Stroke	10,12,14,26,67
Myasthenia gravis	10
Huntington Disease	10,70
Traumatic Brain Injury	14
Spinal Cord Injury	14
Brain Tumor	14
Muscle Disease (Peripheral Myopathy)	19
Respiratory Disease	5,54,78
Unidentified Conditions	9,46,61,62,85

3.2 Diverse Contexts of Difficult Conversations

The literature underscores the pivotal role of effective communication in several diverse contexts with a notable emphasis on the delicate task of delivering distressing news regarding one’s disease. Breaking bad news emerged as the most prevalent central theme, with 37 articles addressing the task of communicating diagnoses across various medical conditions, including cancer, motor neuron disease, infertility, dementia, and Amyotrophic Lateral Sclerosis. Palliative medicine and end-of-life conversations, encompassing advance directives and discussions around death, were explored in 20 articles. Prognosis communication was a subject of interest in 15articles, while 14 explored discussions on treatment, including discontinuation of cancer therapy and treatment failure. The realm of obstetrics, gynecology, and neonatal specialties featured in the literature with 9 articles focusing on difficult conversations surrounding pregnancy abnormalities, miscarriage, ectopic pregnancy, and perinatal loss. Other areas of inquiry included discussions on children's health issues, head and neck cancer, unintended medical outcomes, and general communication dynamics in physician-patient consultations.

Outside the clinical environment, the literature expands into non-clinical contexts, exploring topics such as interpersonal dynamics among couples. This includes discussions on conflict, goal formation, and general communication. Several articles delved into niche areas of inquiry, with only one or two publications addressing each specific topic including care order initiatives for children, intimate partner violence, suicide, and familial discussions touching on autonomy, school-related issues, and finances. Additionally, the exploration of communication between formal caregivers and elderly individuals, involving activities of daily living, and non-verbal behaviors such as eye gaze amongst university students was explored. This highlights the multifaceted nature of communication in healthcare and beyond, particularly within the context of difficult conversations. Table 5 provides a detailed breakdown of the diverse contexts of conversations found within the literature.

Table 5. Context of Conversation Presented in the Literature

Clinical Context	*Article Number*
Diagnosis Communication	3,4,9,10,11,13,16,17,20,22,23,26,27,29,37,38,41,42, 45,47,49,50,51,53,56,57,58,60,62,63,71,72,73,76,77, 78,85
Prognosis Communication	9,14,21,36,38,41,45,46,54,58,60,70,73,76,82
Treatment Communication	9,13,20,21,29,38,41,53,59,60,62,75,82,84
Palliative Care /End of Life/Death & Advance care Directive	3,5,10,11,21,31,32,33,34,45,53,55,60,61,66,67,68, 69,70,78
Obstetrics, Gynecology, and Neonatal Communication	1,15,18,33,34,38,48,57,64
Health Condition/Status of Illness	9,10,11,13,17,19,41,78,79
Child’s Health Condition or Issue	2,42
Disclosing Unanticipated Medical Outcomes	43,75
General communication between Health Care Provider-Patient	7,24,39
Increased Risk of Chronic/Fetal Disease	19
Communicating With Head &Neck Cancer Patients	6
Communicating With aphasic Individual	12

Non-Clinical Context	
Communication Between Couples/Spouses	8,30,40,52,80
Familial Difficult Conversations	28
Care Order Initiatives	74
General Communication (i.e. Student, Supervisor etc.)	35
Intimate Partner Violence	43
Relational Value Through Eye Gaze	83
Suicide	25,43
Communication Between Formal Caregivers and Elderly Individuals	81,85

3.3 Thematic Summary of Strategies for Consideration when Undertaking Difficult Conversations

Findings extracted from the 85 articles were grouped into the following 7 key themes: i) selecting an appropriate physical environment (39 studies); ii) conversation preparation (52 studies); iii) verbal communication skills (55 studies); iv) non-verbal communication skills (52 studies); v) post-conversation actions (37 studies); vi) care partner character attributes (62 studies); and vii) existing communication frameworks tailored for navigating difficult conversations (19 studies). The studies included emphasize the utility of employing these components in fostering effective communication during challenging discussions.

3.3.1 Selecting an Appropriate Physical Environment

The prevailing factor emphasized in choosing an optimal setting for engaging in difficult conversations was privacy. Out of 85 articles, 29 emphasized the necessity for a secluded environment that ensures confidentiality, shielding the conversation from the observation, proximity, or interference of individuals not directly participating in the discussion. There were 13 articles that advocated for the selection of a quiet environment that is free of noise and distractions that may otherwise disrupt the conversation. Additionally, 19 articles recommended opting for a setting that minimizes interruptions, suggesting measures such as turning off electronic devices (i.e. phone, pager) and not interrupting a partner when they speak. Regarding the physical arrangement of communicators' bodies, 12 articles highlighted the importance of ensuring that partners are positioned at the same physical level, such as in a seated position, to facilitate a direct line of sight and face to face communication. Six articles proposed that difficult conversations take place in a "comfortable" environment. Five articles advised the removal of any physical barriers between partners that might act as distractions or hinder the flow of communication. Two articles emphasized the significance of refraining from conveying bad news via telephone. Lastly, one article highlighted the importance of conducting conversations in a safe environment that is conducive to engagement in open, honest communication. Table 6 provides a detailed breakdown of the characteristics related to the physical environment in the included articles.

Table 6. Physical Environment Characteristics to be Mindful of During Difficult Conversations

Physical Environment Characteristics	*Article Number*
Privacy	1,2,3,11,13,14,15,17,18,19,20,23,29,32,33,37,38,41,45,47,50,53,56,59,60,62,63,64,71
Quiet Environment	15,18,19,22,32,34,37,38,45,47,48,59,71
No Interruptions	2,3,13,18,20,22,23,25,29,32,33,34,47,48,50,62,64,75,85
Communication Partners Positioned at the Same Level	1,4,18,23,25,33,38,43,47,50,52,63
Removal of Physical Barriers	13,18,23,25,50
Comfortable Environment	11,13,18,19,23,48
Conversation Not via Telephone	18,34
Safe Environment	30

3.3.2 Conversation Preparation

During the preparation for effective communication, 35 articles underscore the importance of ensuring there is an appropriate amount of time to hold the difficult conversation and attend to important conversational components (Table 7). Four articles recommend allowing ample time for the communication partner to pose questions and receive thoughtful responses. Three articles advocated for a sufficient duration to enable communication partners to express their emotions, while three articles propose dedicating adequate time for appropriate responses and effective management of displayed emotions. Additionally, one article suggests there should be ample time for individuals with slowed cognition, such as those with severe aphasia, to think and respond while communicating. Six articles mention the importance of choosing an appropriate time conducive to engaging in a difficult conversation for the carer and/or care recipient. This choice may be predicated upon various factors including the care recipient’s emotion state of mind, psychological and physical status, or availability of support resources.

Before proceeding with the conversation, nine articles believe it's vital to understand the care recipient’s status. It may involve identifying their biopsychosocial, cognitive, and emotional condition, and, in cases, their degree of cognitive impairment and capacity. These observations in the preparation stage are vital as individual may find it difficult to understand or retain information effectively in certain states. As the communicator, 10 articles recommend being ready to participate in challenging conversations. Among these studies, two articles propose understanding the details you intend to share, one article suggests noting down essential information for discussion, two articles recommend engaging in mental rehearsal before conversing, and another article underscores the importance of setting an agenda. Furthermore, one article discussed the creation of a script to be used as a communication application to curb a level of uncomfortableness that may emerge in such conversations. Five articles highlight the importance of being mindful and ready for a variety of emotions and reactions that may be triggered by the disclosure of distressing information.

One article emphasizes that the process of delivering difficult news commences with establishing clear goals. Before engaging in difficult conversation, 23 articles advise the communicator to assess the care receiver’s level of prior knowledge regarding the topic of conversation, by inquiry about what they currently know. In addition, 21 articles recommend explicitly asking and gaining an understanding about the amount of information the care receiver would like to obtain from the difficult conversation. Table 7 provides a detailed breakdown of the strategies related to conversation preparation in the included articles.

Table 7. Conversation Preparation Strategies to Utilize During Difficult Conversations

Conversation Preparation Strategies	*Article Number*
Sufficient Time to Hold Conversation	2,3,4,11,13,17,19,22,23,24,25,26,29,32,33,36,37,38,41,42,45,47,50,53,55,56,59,60,62,63,71,75,79,80
Sufficient Time for Questions & Answers	1,2,22,42
Sufficient Time for Emotional Expressions	3,22,63
Sufficient Time for Appropriate Response & Management of Emotions	3,29,47
Sufficient Time for Individuals with Slowed Cognition to Communicate	12
Selecting an Appropriate Time to Engage in Difficult Conversation	11,13,14,19,20,23
Understanding Care Receiver's State	11,13,14,19,20,36,62,63,76
Preparation Attributes by the Communicator	Being Prepared to Conduct Difficult Conversation: 22,23,42,62,63,71,74,78,79,84, Know the Details you Intend to Share: 62,63 Make Note of the Essential Information to be Discussed: 62 Mentally Rehearse Before Conversing: 62,74 Create a Script: 82 Set an Agenda: 84 Prepare for Communication Partner's Emotions: 13,20,38,48,66,

	Clear Goals for the Conversation: 79
Assess Communication Partner's Prior Knowledge	2,3,13,20,23,33,34,38,41,47,48,50,51,53,60,61,62,63,76,77,79,82,84
Inquiry into Level of Information Communication Partner Would like to Obtain	2,3,5,10,11,19,23,38,46,47,50,51,53,54,60,62,63,76,77,79,82

3.3.3 Verbal Communication Skills

To initiate the disclosure of challenging information, nine articles advise the deployment of a phrase to prepare their communication partner in advance about forthcoming information that may be potentially difficult to receive. Various labels for these phrases included “warning shots,” “gentle warnings,” “forecasting,” and “headline statements.” Subsequently, two articles emphasize that a “warning shot” in conversation may be a confusing or alarming practice for a certain subset of individuals, particularly those with intellectual disabilities. One article encourages the communicator to explicitly state their benevolent intentions before giving candid opinion/feedback to clearly highlight that the discussion is rooted in a well-meaning disposition. According to two articles, the communicator should explicitly verbalize the reason/purpose of the conversational meeting. Seventeen articles suggest seeking an invitation and obtaining permission before sharing sensitive information to demonstrate respect and consideration for the care receiver, especially when broaching delicate topics including delivering bad news. Fourteen articles encourage the communicator to break down information into smaller, more manageable pieces to help their partner understand what is being communicated. One article notes that it may be more conducive to avoid sharing information “drop-by-drop” when conversing with individuals who have dementia as they may find this type of revelation increasingly confusing.

When engaging in a difficult conversation, 32 articles highlight the importance of appropriate vocabulary, particularly the use of non-technical words, simple and direct language. Therefore, the communicator should avoid using medical jargon, euphemisms and/or ambiguous language, thus reducing potential confusion or misunderstanding during the conversation. A single article highlights the signific of employing age appropriate language. . To establish a strong partnership between carer and care recipient, one article suggests employing language that strengthens a sense of “us” rather than a hierarchal partnership. Eleven articles emphasis the use of open-ended questions to facilitate communication and gain the perspective of their partner. Additionally, two articles propose the use of closed-ended question as a communication strategy that has been presented as being effective for caregivers of individuals with Alzheimer’s disease. Six articles advised delivering information and communicating at an appropriate pace, allowing for conversation components including inquisitions and emotional response, while five articles emphasized the importance of employing a modulated tone of voice. Seven articles advocate for checks on your partner’s comprehension of the knowledge presented during the conversation. Table 8 provides a detailed breakdown of the verbal communication skills presented in each of the included articles.

Table 8. Verbal Communication Skills to Utilize During Difficult Conversations

Verbal Communication Strategies	*Article Number*
Preparation Statement	13,18,23,34,38,47,50,76,77
Anti-Headline Statement	76,77
Benevolent Intentions	35
Verbalize Reason/Purpose of Conversation	11,63
Seek Communication Partners Permission to Proceed	2,3,10,13,19,20,33,36,38,42,47,50,56,60,64,72,84
Present Information in Small Quantities	2,13,14,17,20,21,27,33,34,37,62, 73, 76,77
Avoid “Drop-by-Drop” Information Sharing	63
Appropriate Vocabulary: Simple Language	3,4,5,6,11,13,14,15,18,19,22,23,32,33,34,36,37, 41,47,48,50,60,61,62,63,64,71,75,78,80,82,83
Appropriate Vocabulary: Age-Appropriate Language	32
Appropriate Vocabulary: “Us Language”	19
Open-Ended Questions	10,13,25,32,41,44,46,53,78,80,82
Close-Ended Questions	80,81
Appropriate Pace	8,20,23,24,26,36
Tone of Voice	24,36,44,58,80
Comprehension Checks	20,34,53,62,63,76,84

3.3.4 Non-Verbal Communication Skills

For effective communication during difficult conversations, the literature emphasizes several non-verbal skills may be employed. Twenty-three articles propose that maintaining eye contact serves as a positive communication method, aiding in the facilitation and expression of attentiveness during interactions. Fourteen articles underscore the importance for carers being attentive listeners, to ensure the care recipient feels heard and understood. Among these articles, five go beyond mere listening and recommend caregivers to be "active listeners," providing actionable steps such as acknowledging and repeating information, as well as summarizing. One article proposes that effective communication involves listening "carefully," which they regard as waiting for a moment after the care recipient stops speaking to check if they have additional thoughts to share. Thirteen articles encourage the use of physical touch to convey reassurance and comfort during the difficult conversation. For example, this may include a soft touch on the arm, holding of the hand or hugging. Ten articles recommended the tolerance and respect for silence, highlighting this could create a space where the communication partner is more compelled to share their thoughts. Two articles highlight the importance of incorporating pauses in challenging conversations, thereby showcasing a patient-centered interaction, and facilitating the absorption of information.

Nine articles speak to the significance of a communicator’s body language during conversation. Within this set, three articles talked about the use of body language, as a form of communication, in an unspecified manner, six recommend adopting a slight forward lean towards their partner, and four articles highlight additional body attributes to be mindful of, including direct body orientation, relaxed postural openness, proximity, and unfolded arms. Eight articles encourage the communicator to utilize facial expressions and body gestures to assist with the intelligibility of communication, including smiling when appropriate or providing affirmative head nods to acknowledge their partner. Furthermore, three article suggests that the communicator delivering unfavorable news should be able to observe the communication partner’s body language and/or facial expression. This includes observing signs such as eyes glossing over or the partner looking away during the interaction. Based on the gathered information, adjustments to the conversation, such as tailoring the message to the individual, can thus be made.

Twenty-seven articles recommend the carer attend to the care recipient's emotions. This act of engaging can be accomplished through the observation, identification, response, acknowledgment, management, and validate of the emotions that present because of difficult conversations. Two articles addressing the dementia population highlighted the importance of assisting individuals in comprehending their emotions and assigning them a name. Additionally, two articles speak to the exploration of these emotions, and with adequate time available, digging deeper into care recipient's emotions to facilitate the disclosure of difficult news. Table 9 provides a detailed breakdown of the non-verbal communication skills presented in each of the included articles.

Table 9. Non-Verbal Communication Skills to Utilize During Conversations

Non-Verbal Communication Strategies	*Article Number*
Eye Contact	2,8,11,13,19,23,24,25,34,39,40,41,44,50,52,58,60,61,64,75,80,83,85
Attentive Listening	6,13,14,15,19,20,25,32,36,44,48,53,60,75 Active Listening: 6,13,19,44,53 Careful Listening: 75
Physical Touch	2,6,8,23,32,34,39,50,60,65,66,80,85
Tolerance & Respect for Silence	5,13,22,46,48,61,62,63,64,66
Communication Pauses	13,38
Body Language: Unspecified	6,74,85
Body Language: Slight Forward Lean	8,11,13,25,39,58
Body Language: Additional Body Attributes (Orientation, Openness, Proximity, Unfolded Arms)	8,13,25,39
Facial Expression & Gestures of Communicator	6,8,25,39,52,58,81,85
Observe Communication Partners Body Language & Facial Expression	19,38,45

Attend to Communication Partner’s Emotions	3,11,13,14,17,19,20,23,29,32,33,35,38,42,44,45, 47,50,51,53,60,62, 63,64,66,76,84
Assist in the Comprehension of Emotions	22,63
Further Exploration of Emotions	2,32

3.3.5 Post Conversational Actions

Upon the conclusion of a difficult conversation, there are various post-conversational actions that one may engage in to effectively bring the discussion to a close (Table 10). Among the 85 articles, 22 propose the formulation of a strategic action plan, emphasizing the importance of collaborative development and specifying practical steps forward for progress. Eleven articles also propose the inclusion of a follow-up meeting in the plan, asserting that this serves practical measure to manage concerns and anxiety until the next communicative opportunity, where thoughts and feelings arising from the difficult conversation can be addressed. Aligning with this perspective, three articles propose that caregivers play a crucial role in comprehending, proposing, emphasizing, and encouraging attainable and realistic goals during discussions of this nature. In 11 articles, it is suggested that the communicator concludes the discussion by summarizing what has been covered, aiming to reinforce key points and strengthen the message they sought to convey. Additionally, four articles introduced the utilization of summarization or comprehension checks in the form of questions as a tool employed by communicators to assess the care recipient's comprehension of the difficult conversation. This approach also afforded the caregiver the opportunity to address any misunderstandings before concluding the conversation.

Following the difficult disclosure of bad news, 13 articles highlighted the importance of providing further resources and identifying a support network that may be helpful for the communication partner to cope with or understand more greatly what has just been conversed. This may include the introduction to support groups, engagement of allied health professionals, chaplaincy, psychological support services, community organizations, educational brochures and internet resources that can be utilized at an appropriate time of their discretion. Table 10 provides a detailed breakdown of recommended post-conversational actions presented in each of the included articles.

Table 10. Post-Conversational Actions to Utilize During Difficult Conversations

Strategies	*Article Number*
Strategic Action Plan	2,13,17,20,23,27,33,3738,42,47,48,58,62,64,71,72, 74,76,79,82
Follow-up Meeting	2,10,11,13,38,42,47,50,53,63,75
Creation of Realistic Goals	3,13,37
Summarize Conversation	2,12,18,20,23,33,38,53,60,72,84
Assess Communication Partner's Comprehension	2,11,13,38
Provide Resources & Supports	2,3,10,13,22,32,34,36,42,50,53,56,63

3.3.6 Care Partner Character Attributes

Throughout the included articles, an emphasis was placed on potentially beneficial character traits that may be helpful for the communicator to display during a difficult conversation (Table 11). Health care professionals, informal care partners and patients have expressed a shared sentiment as to the type of interactions they would prefer, as it pertains to the conduction of difficult conversation, by outlining the human qualities one ought to poses for satisfactory communication. Of the 85 articles, 37 encourage carers to remain empathetic throughout the difficult conversation, 28 articles recommend the communicator to be honest and maintain realistic hope, 13 articles encourage the carer to be sensitive to the nature of the conversation and the feelings of their communication partner, 12 articles encourage the expression of compassion, five articles encourage the carer to remain sympathetic, four articles recommend the communicator to remain calm, and one article encourages the carer to remain sincere through the duration of the conversation. Table 11 provides a detailed breakdown of recommended care partner character attributes presented in each of the included articles.

Table 11. Care Partner Character Attributes

Character Traits	*Article Number*
Empathetic	1,2,3,4,6,11,13,14,15,16,19,20,23,25,32,33,34,36,38,39,41,42,44,47,48,49,50,51,53,56,57,58,60,61,63,66,84
Honest	2,3,5,9,14,15,16,19,21,23,26,32,34,35,38,41,46,50,51,54,60,62,67,71,77,78,79,82
Hopeful	2,5,9,11,13,14,16,18,19,23,31,32,37,38,42,45,46,49,54,58,59,60,62,67,71,73,79,82
Sensitive	3,5,16,23,26,27,32,36,47,53,56,57,64
Compassionate	2,13,14,23,32,34,42,44,49,60,61,62
Sympathetic	1,19,20,32,72
Calm	3,34,80,81
Sincere	4

3.3.7 Communication Frameworks

The literature presents evidence-based communication frameworks, also labeled as talking maps and guides, that can be utilized to enhance provider-patient communication regarding a plethora of situation (Table 12). The *SPIKES protocol*, featured in 18 articles, was the most extensively discussed. It takes a structured procedure for communicating undesirable information, commonly referred to as "breaking bad news," employing a six-stage methodology. Furthermore, a variety of communication models tailored to breaking bad news within the medical community were explored in the literature. The *GUIDE* framework was the subject of discussion in a single article, *Kays' 10-step approach* in another, and the *Consensus guidelines* in three articles. Notably, one article emphasized the utility of the *ADAPT* framework for communicating prognosis, while frameworks like the *Serious Illness Conversation Guide* and *REMAP* were introduced as tools for guiding discussions on care goals in separate articles. In a single article, emphasis is placed on the utility of the *NURSE* mnemonic as a valuable tool for effectively addressing emotions in various patient encounters. The *Calgary-Cambridge Observation Guide,* a recognized framework, was referenced in three articles, serving as a guide for healthcare professionals on effective communication during medical interviews. One article mentions *SEGUE* framework, commonly utilized to facilitate the teaching and assessment of communication skills in medical learners. Finally, the *ABCDE* framework was discussed in two articles, *BREAKS* was explored in two others, while EMPATHY, mentioned in one article are all communication models designed to support the delivery of distressing information and navigate difficult conversations. Table 12 provides a detailed breakdown of evidence-informed communication frameworks presented in the included articles.

Table 12. Communication Frameworks

Frameworks	*Article Number*
SPIKES	2,3,10,13,19,20,33,36,38,42,47,50,56,60,63, 64,72,84
GUIDE	38
Kays' 10-Step Approach	64
Consensus Guidelines	19,41,60
ADAPT	38
Serious Illness Conversation Guide	38
REMAP	38
NURSE	38
The Calgary-Cambridge Observation Guide	13,19,64
SEGUE	19
ABCDE	13,42
BREAKS	13,64
EMPATHY	42

Chapter 4

4 Discussion

The thematic findings of this scoping review have provided a multitude of strategies that could be applicable for informal care partners to aid in the navigation of difficult conversations. Amongst the included articles, the results have showcased various communication attributes to be mindful of to support of effective communication. These elements range from choosing a conducive physical environment, the adoption of certain verbal and non-verbal skills, to personal character attributes that the literature recommends a communicator exhibit.

Collectively, the findings of this research highlight the significance of tailoring communication strategies to individual’s needs, emphasizing the pivotal role of demonstrating empathy, and the imperative of enhancing communication skills through education and training initiatives. Each of these aspects will be elaborated upon in the following section to provide a comprehensive understanding of their importance and applications in the context of facilitating effective communication in caregiving settings.

4.1 Tailoring Communication Strategies

The findings highlighted various strategies that were consistently recommended including an emphasis on privacy, communicating using simple and understandable language free of euphemisms or jargon, being cognisant of having sufficient time to hold the conversation, choosing to listen attentively, and maintaining eye contact with your partner. While these strategies can prove useful and appropriate for many individuals engaging in challenging conversations, several articles emphasize the significance of employing a tailored approach. They recommend that certain strategies may not universally apply and should either be adapted or avoided altogether to better align with the needs of the conversational partner. This approach aims to enhance the facilitation of dialogue by customizing techniques to suit the specific dynamics of the conversation.

For example, the utilization of "warning shots," a term denoting a preliminary communication to prepare a partner for potentially challenging information, and the practice of presenting information gradually, known as the "drop-wise" approach, to avoid overwhelming the recipient, exemplify verbal communication strategies that may not be universally applicable. While some individuals may find these strategies helpful in facilitating difficult conversations, literature suggests that it may not be advisable for communicators to employ "warning shots" or the "drop-wise" technique when conversing with someone who has a cognitive impairment (Tuffrey-Wijne, 2010; Tuffrey-Wijne, 2013; Derksen et al., 2006).

It is believed the use of a "warning shot," employed prior to disclosing distressing news, could potentially confuse or alarm certain communication partners (Tuffrey-Wijne, 2010; Tuffrey-Wijne, 2013). Similarly, Derksen and colleagues (2006) cautioned against employing gradual information disclosure, such as the drop-wise method, with individuals suffering from dementia, as it may lead to increased confusion and impede effective communication, contrary to the intended goal of employing such strategies to enhance communication flow.

Another example highlighted within the current findings is the selective use of open-ended questions. While open-ended questions have been advocated to facilitate and encourage open dialogue (Kuttner, 2007), research suggests that phrasing questions in a manner that allows for a broad range of responses may hinder communication within populations experiencing cognitive deficits (Pérez Mantero, 2014). In contrast, studies have indicated that successful communication between care partners and individuals with dementia often involves the use of closed-ended questions (requiring yes/no responses) as an effective means of interaction (Small & Perry, 2005; Wilson et al., 2012; Ripich et al., 2000). This type of questioning prompts a controlled response of confirmation or denial, imposes less cognitive burden, and requires less demand on memory compared to open-ended questions (Ripich et al., 2000; Acton et al., 2007).

The adjustments made to conversation approaches to better suit the cognitive abilities of individuals with dementia are highly applicable to care partners of IWPD because both conditions lead to cognitive impairments (Williams & Parker, 2012; Fang et al., 2020). The neurodegeneration associated with both conditions can result in difficulties in memory, attention, verbal fluency, and executive processing (Park & Stacy, 2009; Mosley et al., 2017; Stopford et al., 2012; Henry et al., 2004). Therefore, there is an overlap in suggested communication strategies that can enable conversation with both subsets of people. The Parkinson Society of British Columbia (2016) shared a resource targeting the enhancement of communication with IWPD. These strategies closely resembled those advocated for in the dementia literature, including the use of closed-ended questions, selecting an appropriate environment free from distraction, and allowing time for your partner to respond (Peixoto et al., 2020).

Additionally, the parallels regarding cognitive impact are even more significant because dementia is considered a clinical consequence for IWPD (Janvin et al., 2005). In an 8-year longitudinal study of IWPD, Aarsland et al. (2003) identified that the prevalence of developing dementia was 78.2%. Similarly, a systematic review including 295 studies found that 25% of PD patients were diagnosed with dementia (Severiano E Sousa et al., 2022). Therefore, due to the shared characteristic of cognitive impairments in both PD and dementia, the strategies outlined in the articles included in this scoping review focusing on individuals with dementia have the potential to be highly applicable, and their implementation may be beneficial for care partners of IWPD.

Each of the examples provided above emphasize the idea that there is no one-size-fits-all approach, and that there is significant benefit from taking a tailored approach when selecting strategies to adopt during difficult conversations. These findings align well with those of Brooks and colleagues(2017) who published on the importance of tailoring interactions to meet older adults' health literacy needs. Specifically, the authors reported that a lack of tailored information appeared to be a barrier, and that regardless of an individual's assessed health literacy, they valued information being delivered in a clear and simple manner.

4.2 Communication in a Non-Clinical Environment

Although findings included a scarcity of literature specifically addressing interaction between informal care partners and care recipients within difficult conversations, several articles explored broader communication dynamics within spousal or couple relationships. Navigating effective communication in a partnership can be challenging, however it's importance cannot be overstated as research has shown that effective interpersonal communication correlates with improved emotional and physical well-being and reduced caregiver burden (Porter et al., 2005; Lobchuk & Degner, 2002; Ketcher et al., 2020).

Unfortunately, despite the desire for open communication between a care partner and care recipient dyad, and the accumulation of its positive impacts, this openness can often be hindered by a phenomenon known as "protective buffering." Protective buffering serves as a coping strategy that supresses self-disclosure by concealing personal worries, dismissing concerns, and complying with a partner to avoid conflict (Suls et al., 1997; Ketcher et al., 2020; Perndorfer et al., 2019). To address protective buffering and foster improved communication, Ketcher and colleagues (2020) advocate for the implementation of goal setting. This builds on the work of Canevello & Crocker (2017) who identified that even during difficult conversations, individuals who maintain compassionate goals for their partner tend to adopt more cooperative mindsets afterward, which in turn fosters a sense of interpersonal ease and connection in the relationship. Compassionate goals emphasize attentiveness to the needs of others and demonstrate a display of supportiveness (Jiang et al., 2023; Niiya & Crocker, 2019; Canevello & Crocker,2017). This approach not only facilitates interpersonal ease and connection but also cultivates a more constructive and empathetic dialogue within the relationship. Such an approach is especially significant considering current findings that indicate empathy is the most frequently cited attribute that care partners may find helpful to display during a difficult conversation. Further elaboration on this topic will be provided in the subsequent section.

4.3 Communicating with Empathy

Within the literature, empathy emerges as an important foundational element in effective interpersonal communication, gaining particular significance when navigating difficult conversations (Levy et al., 2022). The word empathy is influenced by the German word "*einfuhlung*" (meaning "in-feeling") and encompasses the capacity to understand and vicariously experience the emotional state of another while retaining a perceptive stance (Cuff et al., 2016; Frankel, 2017; Hardee, 2003; Albiero et al., 2009; Decety & Lamm, 2006). The empathetic understanding and acknowledgement of another's emotional state and perspective is crucial in interpersonal conversation as it enables the building and strengthening of trust, promotes open dialogue, enhances cooperation and in close relationships, is related to relationship satisfaction (Fuller et al., 2021; Ferguson et al., 2021; Wu et al., 2022; Verhofstadt et al., 2016).

Current research underscores the significance of empathy as one of the most crucial character attributes of effective communication, particularly in clinical settings where interactions occur among healthcare professionals, patients, and their accompanying family members. The desire for an empathetic physician is frequently voiced by patients and their families, particularly in the challenging circumstances of receiving unfavorable news such as a diagnosis of a life-limiting medical condition or learning of a poor prognosis (Alkazaleh et al., 2004; Atasoy et al., 2012; O'Connor, Aoun, & Breen, 2018).

Communicating empathetically can take various forms, including approaching difficult topics in a warm and caring manner, not avoiding discussions regardless of the subject, and directly addressing the emotions of communication partners (Choe et al., 2019; Bor et al., 1993). Fuller and colleagues (2021) highlight that empathy is made up of key dimensions, comprising of cognitive and affective aspects. Cognitive empathy involves understanding the thoughts and emotions of another person (Verhofstadt et al., 2016; Fuller et al., 2021), with "perspective taking" being a prominent aspect (Davis, 1983). A demonstration of cognitive empathy occurs when a communicator, such as a physician, strives to comprehend a patient or caregiver's perspective. This understanding may involve validating emotions or concerns such as addressing feelings of fear related to disease management choices, or gaining insight into why an individual may be reluctant to engage in certain difficult conversations (Dias et al., 2003; Rassin et al, 2006).

On the other hand, affective empathy is perceived as an individual's instinctive, internal emotional reaction to the emotional state of another person (Verhofstadt et al., 2016; Ioannidou & Konstantikaki, 2008). Affective empathy entails experiencing similar emotions to those expressed by the other person, often referred to as “mirroring” (Ferrari & Coudé, 2018). For instance, when a spouse expresses sadness, affective empathy may lead the listener to feel a sense of sadness themselves, reflecting the emotional state of their partner. This mirroring of emotions is a natural response that allows individuals to connect emotionally with others and understand their feelings on a deeper level (Ferrari & Coudé, 2018).

Importantly, evidence indicates that individuals with PD often experience a decreased ability to detect emotions and display empathy (Martinez et al., 2018). Interestingly, caregivers are often unaware of these deficits and tend to overestimate their partner’s ability to detect emotions. This lack of awareness may lead to communication breakdowns as the caregiver becomes frustrated with their partner not responding to non-verbal cues that display emotions such as annoyance or displeasure which may lead the care partner to feel unappreciated, leading to low mood and burnout (Martinez et al., 2018). Similarly, care partners of IWPD may also face their own challenges with respect to demonstrating empathy towards the care recipient. This is not surprising as PD often requires long-term care, with symptoms worsening over time and individuals becoming increasingly dependent on their care partners. This ongoing decline in health and functioning can be emotionally distressing for the care partner and can lead to increased level of anxiety, stress, and ultimately caregiver burnout (Mosley et al., 2017). Notably, evidence suggests that care partners who experience increased levels of stress and burnout are less likely to provide empathetic care (Martinez et al., 2018), and that diminished empathy is amplified when a lack of reciprocal understanding is present (Aamodt et al., 2023).

Improving empathetic care is crucial, as research suggests that better patient outcomes are associated with care delivered in an empathetic manner (Steinmair et al., 2022). Therefore, understanding and addressing communication and empathy deficits in both individuals with PD and their care partners is essential for maintaining effective communication and ensuring the well-being of both parties. To address the potential deficits in empathy demonstrated by care partners of IWPD, Martinez et al., (2018) recommend a two-pronged approach. First, they suggest that future research explore interventions aimed at informing care partners that decreased emotion detection and empathy can be part of the disease process. Additionally, these authors propose increasing competence in emotion detection by instructing care partners to provide additional cues to patients related to their emotions. For example, they recommend care partners to plainly state their feelings without assuming patients can detect emotions solely through facial cues or body language.

Furthermore, additional research suggests that empathy is a skill that may be strengthened through various interventions. A systematic review conducted by Nembhard (2023) analyzed findings from 128 studies that evaluated interventions designed to improve empathy. These interventions took various forms, with over 78% of studies demonstrating a positive and significant effect. Particularly noteworthy is that one of the methods used to enhance empathy was providing training to teach participants how to improve their communication skills. This presents an opportunity for strategies highlighted in this thesis to be utilized to enhance empathy among care partners of IWPD. By focusing on improving communication skills and understanding the unique needs and experiences of their loved ones, care partners can cultivate greater empathy and provide more effective support throughout the progression of PD.

4.4 Improvement of Communication Skills Through Education & Training

Just as empathy has been deemed an acquirable skill that can be taught and learned, the literature also emphasizes the need to provide education and training of communication skills for health care professionals and informal care partners (Platt & Keller, 1994; Decety & Ickes, 2009; Riess, 2017; Aoun et al., 2017; Johansson et al., 2020). Existing literature is saturated with the concept of health care professionals possessing strong communication skills, a necessity identified for carrying out an important facet of their occupation which entails navigating difficult conversations. Discussions around diagnosis, prognosis, test results, and care options have been deemed as being challenging, but are fundamentally important to the trajectory of care for patients (Pastor et al., 2016).

Communication is a core competency of physicians and as such, there is advocacy for investment of time and resources into training this skill (Parker et al., 2009). This imperative for effective communication has led to the development of evidence-informed communication frameworks, which have been utilized to educate health care professionals and hold potential applicability beyond formalized clinical contexts. Baile and colleagues (2000) introduced one of the most well-known protocols for disclosing unfavourable information, encapsulated in the mnemonic SPIKES. This six-step strategy includes: Setting up, Assessing perception, Obtaining invitation to share, Giving knowledge and information, Addressing emotions with empathetic response, and Creating a strategy and summary. The SPIKES protocol was created in alignment with a consensus among oncology patients and healthcare professionals regarding essential elements that should be present in breaking bad news. It provides a standardized approach to initiating difficult conversations (Rosenzweig, 2012) and can be further enhanced by leveraging various strategies identified in the present research findings.

Interestingly, the field of oncology, a specialty that is seeing a rapid increase in patients with approximately 18 million new cases per year globally and was prominently featured in the current scoping review findings, continues to serve as an important center for learning about successful communication strategies, education, and training (Patel et al., 2019). To date, there are various education avenues that have been utilized to teach health care professionals communication skills including didactics, simulation-based curriculum, role-play, and interactive theater (Almaiman et al, 2021; Trickey et al., 2017; Baile & Blatner, 2014; Pastor et al., 2016). However, regardless of the mode of educational delivery, it is important to remember that an essential consideration when implementing educational initiatives is to cater to the learning needs of the target audience. It's widely acknowledged that adults have distinct learning requirements compared to children, owing to differences in age, maturity, and accumulated life experience (Wang, 2011; Knowles et al., 2005). Therefore, exploring teaching modalities prevalent in clinical settings, such as simulation-based training, which is fundamentally rooted in adult learning theory, can offer valuable insights for enhancing educational interventions aimed at adults across diverse contexts (Wang, 2011; Baile & Blatner, 2014).

Given that effective communication relies on the collaborative efforts of both the IWPD and their care partner, it is notable that conventional therapy methods have primarily concentrated on speech production and solely involved the individual with PD. For example, communication difficulties in PD have traditionally been addressed through speech-language therapy targeting specific symptoms of the disease (Johansson et al., 2020). The Lee Silverman voice treatment intervention has been a notable approach employed to enhance voice loudness and intelligibility in IWPD (Spurgeon et al., 2015; Clay et al., 2023; Pu et al., 2021; Ramig et al., 2001). While speech-language therapy has demonstrated benefits for many IWPD (Muñoz-Vigueras et al., 2021) treatment tends to focus on the cognitive and linguistic bases of communication deficits and does not consider the interpersonal relationship dimension of communication (Small & Perry 2012). To address this limitation, a growing body of literature has advocated for communication partner training (CPT).

CPT involves collaborative therapeutic efforts between a person facing communication challenges and their communication partner (i.e. spouse, kin etc.) (Simmons-Mackie et al., 2010). CPT has been recognized for its ability to enhance communication skills and involvement of partners in conversations (Morris et al., 2018; Simmons-Mackie et al., 2010). Its efficacy has been observed across various conditions including aphasia, traumatic brain injury, and dementia (Simmons-Mackie et al., 2016; Johansson et al., 2020; Behn et al., 2020; Volkmer et al., 2021).

In the context of PD, there exists a notable paucity of research on CPT. A pilot study by Forsgren and colleagues (2013) examined adapted CPT among just three PD-spouse dyads. While results were promising, the efficacy of CPT in the PD population remains uncertain. Recognizing this gap, Clay et al. (2023) have published a protocol paper for a feasibility study geared towards evaluating the practical implementation of CPT among IWPD and their respective care partners. This research stands as an important step in not only gauging the acceptability and feasibility of a CPT program tailored specifically for this demographic but also in shedding light on its potential effectiveness.

The forthcoming insights expected from this ongoing investigation hold the potential to offer invaluable guidance for the formulation of future CPT initiatives, precisely tailored to address the multifaceted needs of IWPD and their care partners. As we look ahead, there exists significant opportunity to leverage the diverse strategies elucidated within the findings of the current study. These insights can serve as foundational pillars for informing the development or refinement of CPT programs, strategically crafted to cater to the specific and nuanced requirements of this distinct population. Such endeavors promise to enhance the efficacy and relevance of communication interventions within the PD community, ultimately fostering improved quality of life and communication outcomes for those affected by the disease.

4.5 Gaps in Literature

Although many findings explored communication between patients and health care professionals within a clinical context, there was a paucity of literature directly addressing the facilitation of difficult conversations between informal care partners and care recipients. While the included articles in this review offered many strategies that may translate well to the dyadic relationship between care partners and care recipients, the paucity of literature involving communication strategies specific to informal care partners signifies a critical gap. For example, there could be nuances of interpersonal communication that may take place in close, personal relationship such as those between care partner and their spouse that are absent in professional relationships and consequently, not captured in the existing literature.

Additionally, we identified an absence of literature addressing the assistance and navigation of difficult conversations specifically in the PD population. Given that PD is associated with known communication deficits including both language production and comprehension difficulties (Holtgraves & Cadle, 2016), strategies that take into consideration the unique disease symptomology are warranted. Expanding research in these areas can provide valuable insights into effective communication strategies tailored to the needs of informal care partners and IWPD, ultimately improving the quality of care and support provided within these relationships.

4.6 Limitations

This thesis offers valuable insights into evidence-informed communication strategies crucial for facilitating and navigating challenging conversations. However, several notable limitations inherent in this study require acknowledgment and consideration. Methodologically, the inclusion and exclusion criteria represent a constraint, as the search strategy was restricted to English language articles. Consequently, this scoping review may have unintentionally excluded relevant literature published in languages other than English. This limitation could potentially overlook valuable insights and perspectives offered in non-English publications, thereby limiting the comprehensiveness and diversity of the synthesized evidence base.

Furthermore, unlike systematic or meta-analysis reviews, scoping reviews do not assess the quality of included studies. The absence of quality assessment may impede the ability to critically evaluate the reliability and credibility of the synthesized evidence, thereby impacting the overall robustness of the review.

Another limitation of the present thesis is the omission of the final step of the scoping review framework, which involves consultation with stakeholders to refine the interpretation of results. The absence of stakeholder consultation may restrict the comprehensiveness of perspectives considered in interpreting the findings. However, it is important to note that a consultation phase is planned to be undertaken in a subsequent Delphi study. While beyond the scope of this thesis, the forthcoming Delphi study will provide an opportunity to incorporate diverse stakeholder input, including care partners and healthcare professionals, thus enriching the robustness and relevance of the research outcomes.

4.7 Future Implications

As highlighted earlier, there is a notable gap in the literature concerning tailored communication approaches employed by care partners to facilitate conversations that effectively accommodate impairments associated with PD and promote successful communication. By adopting a more nuanced approach, future research in this domain has the potential to unveil strategies that are better suited and practical for care partners of IWPD, thus enhancing the informal caregiving experience in navigating difficult conversations.

Building upon the insights gained from this scoping review, which provided insight on valuable communication strategies for facilitating effective dialogue, the next step in research involves conducting a Delphi Survey. This survey methodology facilitates the establishment of expert consensus among care partners regarding communication strategies identified in the scoping review that should be prioritized for inclusion in the development, implementation, and evaluation of educational interventions aimed at enhancing care partners proficiency in managing difficult conversations. The forthcoming research findings hold the promise of significantly contributing to the ongoing endeavor to enhance communication and reduce the burden faced by care partners of IWPD.

CHAPTER 5

5 Conclusion

The objective of this scoping review was to systematically examine evidence-informed communication strategies found in the literature that informal care partners of IWPD can utilize to facilitate challenging conversations. The findings from the included articles offer a wealth of practical recommendations. There is a notable emphasis on several overarching themes of communication crucial for fostering effective dialogue. These include attentiveness to the physical environment, readiness for challenging discussions, utilization of communication-enhancing verbal and nonverbal techniques, implementation of post-conversation actions, and embodiment of personal character traits.

Moreover, beyond elucidating strategies for enhancing communication between care partners, this scoping review has also identified potential gaps in knowledge that warrant exploration in future research endeavors. A deeper examination, focusing on the unique dynamics of communication between informal care partners and IWPD, holds promise for enriching both the communication literature and the caregiving experience. Specifically, a nuanced understanding of PD in the context of communication strategies for navigating difficult conversations could prove invaluable.

While challenging conversations will always be part of the human experience, the aspiration is that the evidence-informed strategies delineated in this thesis will make a meaningful impact on improving communication skills. By extension, the aim is to enhance the overall experience of informal care partners who encounter difficult conversations in their caregiving journey.

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Appendices

Appendix 1: Scoping Review Article Legend

Number	Articles
1	Alkazaleh et al., 2004
2	Almaiman et al, 2021
3	Aoun et al., 2017
4	Atasoyet al., 2012
5	Barclay & Maher, 2010
6	Benevenuto Reis., 2018
7	Bensing et al., 2008
8	Bernecker et al., 2019
9	Bertoncello Fontes et al., 2017
10	Boersma et al., 2014
11	Bor et al., 1993
12	Bryan et al., 1998
13	Buchanan, 2017
14	Burton et ak., 2021
15	Canadian Paediatric Society, 2001
16	Chio et al., 2008
17	Chis, 2020
18	Chisholm et al., 1997
19	Choe et al., 2019
20	Cleary et al., 2009
21	Davidson, 2007
22	Derksen, 2006
23	Dias et al., 2003
24	Drew, 1986
25	Gibbs, 1990
26	Hanratty et al., 2012
27	Karnieli-Miller et al, 2007
28	Keating et al., 2013
29	Kebede et al., 2020
30	Ketcher et al., 2020
31	Koh et al.,2017
32	Kuttner, 2007
33	Lefkowits & Solomon, 2016
34	Levetown, 2004
35	Levine, Roberts & Cohen, 2020
36	Levy et al., 2022
37	Links & Kramer, 1994
38	Littell et al., 2019
39	Little et al., 2015
40	Lochman & Allen, 1981
41	Maguire, 1999
42	Maksymowicz, Libura, & Malarkiewicz, 2022
43	Marken et al., 2010
44	Marks et al., 2015
45	Matthews, Baken, & Ross, 2020
46	Maxwell et al., 2020
47	McCluskey, Casarett, Siderowf, 2004
48	McGrath, 2005
49	Merl et al., 2022
50	Mosconi, Vannacci & Ravaldi, 2021
51	Munoz Sastre, 2011
52	Murphy, 2004
53	Newton, 2010
54	Ngwenya, 2021
55	Niranjan, 2018
56	O'Connor, Aoun, & Breen, 2018
57	O'Connell, Meaney & O'Donoghue, 2016
58	Orioles et al., 2013
59	Otani et al., 2011
60	Parker, Aaron, & Baile, 2009
61	Pastor et al., 2016
62	Payán et al., 2009
63	Peixoto et al., 2020
64	Petrita, 2021
65	Planalp & Trost, 2008
66	Rassin et al., 2006
67	Rejnö, Silfverberg, & Ternestedt, 2017
68	Schulz et al., 2017
69	Smith, 2017
70	Sofronas & Wright, 2021
71	Taylor, Warnock & Tod, 2019
72	Tehran et al., 2019
73	Thulesius, Hakansson, & Petersson, 2003
74	Tonning Otterlei & tudsrød, 2022
75	Trickey et al., 2017
76	Tuffrey-Wijne, 2013
77	Tuffrey-Wijne, Bernal & Hollins, 2010
78	Van Keer et al., 2019
79	Weir & Brint, 2011
80	Williams & Parker, 2012
81	Wilson et al., 2012
82	Winner et al., 2017
83	Wirth et al., 2010
84	Wuensch et al., 2013
85	Zaletal et al., 2012

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