# "He said I've just got to learn to be a saint":

# The consumer journey experiences of people with dementia and their families.

#### Abstract

We examine consumer journeys of people with dementia and their caregivers. Too often customer journeys are limited to single consumers in one consumption situation with one firm. In contrast, we study consumer journeys, which transcend single consumption experiences. We include caregivers as 'traveling companions', overcoming the incorrect assumption that journeys are traveled alone. And we examine vulnerable people as opposed to agentic consumers who comprise most journey research. Based on narratives of people with dementia and their caregivers (n=33), we uncovered a journey beset by delays, access barriers, power struggles, and fear. We identified major gaps in service provision, both for the people with dementia themselves and a desperate need for support and respite for isolated and exhausted caregivers. We contribute knowledge in an area neglected by marketing. If the responsible research in marketing movement is to achieve its aim of developing new knowledge for the ultimate purpose of creating a better world, we need to understand the unmet needs and lived experiences of people with dementia and those who accompany them on their journey.

## **Key Contributions**

Customer journey literature has flourished recently, providing insights into a range of holistic consumer experiences, needs, motivations, decision-making processes, and product and service encounters. However, there are several important omissions to current journey scholarship. In this research, we address three such omissions. First, we examine a consumer journey, rather than a customer journey. Consumer journeys include and transcend consumption experiences, providing insights into a more holistic journey experience than is found when a single consumption situation is examined. Second, we respond to calls for empirical work to examine journeys that include 'traveling companions'. The extant literature incorrectly assumes that most consumer journeys are traveled alone. Finally, the bulk of journey scholarship is based on motivated, agentic consumers. In contrast, we examine the consumer journeys of people with dementia and their caregivers, as they navigate a difficult and unfamiliar marketplace.

We make several contributions. First, we provide rare empirical insights into the consumer experiences of an overlooked population. If we, the marketing academe, are to make the meaningful progress advocated by the responsible research in marketing movement, we need to seek out underserved and in-need populations, not matter how hard-to-reach. This small-scale study is testimony that our marketing community is equipped to do so. Second, we contribute to the consumer journey literature, enriching the small amount of knowledge that goes beyond the role of customers to examine more complex situations when consumers navigate several consumption situations as well as facing role transitions. Finally, our work has several implications for practice. We show how communication strategies and system design presents barriers to this vulnerable population. We also highlight opportunities for the leisure industry to provide much needed respite to exhausted travelers.

### Introduction

Recently, the customer journey has made a revival in marketing literature (Tueanrat et al. 2021). Customer journeys identify the touchpoints a customer encounters throughout the stages of the purchase decision and consumption process. A touchpoint is therefore any point of interaction a customer has with any aspect of the brand (Clatworthy 2010). Touchpoints can be tangible or intangible (Zomerdijk and Voss 2010). Customer journeys are recognized as crucial

ways of understanding holistic consumer experiences, providing rich customer insights into needs, motivations, decision-making processes, and product and service encounters (Lemon and Verhoef 2016).

Despite recent progress, we address three identified gaps in the journey literature. The first relates to the consumer - as opposed customer - journey. The term 'consumer' is broader and more extensive than customer (Hamilton 2016), so consumer journeys are more complex, comprising multiple customer journeys in overall goal pursuit (Betterncourt et al. 2022). Second, most studies examine solo customer journeys, which fail to reflect reality because many journeys are traveled with a companion (Hamilton et al. 2021). Finally, most journey research incorporates agentic consumers who have choice. Vulnerable consumers who lack agency are rarely the focus. We bring these gaps together by focusing on the consumer journeys of a particularly vulnerable type of consumer: people with dementia (PwD) who are accompanied on their journeys by family members.

Dementia is a progressive and debilitating condition. While its symptoms manifest differently depending on the individual and dementia type (e.g., Alzheimer's disease or vascular dementia), most sufferers experience problems with memory, cognition, spatial and temporal awareness, communication, behavior, and ultimately tasks associated with daily living (Alzheimer's Society 2023). The numbers of people living with dementia are substantial. Estimates suggest around one million people in the UK (Alzheimer's Society 2023), over 6 million in the US (Alzheimer's Association 2023), and 55 million globally (WHO 2021). The prevalence of global population aging (UN 2020) means these figures are set to rise significantly (WHO 2023). Dementia was proclaimed a public health priory over a decade ago (WHO 2012) and is a growing public health concern (Wilkinson et al. 2019). The financial costs are substantial: in the US alone, the total monetary cost of dementia in 2010 was estimated to be around \$200 billion, of which Medicare paid \$11 billion (Hurd et al. 2013).

Some organizations are responding to this growing market. Assistive technologies include smart home devices and tracking apps (Gibson et al. 2016), memory aids are designed for cognitive stimulation (Bourgeois 2014), and there are increasing number of support groups and facilities for both PwD and caregivers. Nevertheless, the availability of care services is insufficient, and offerings frequently fail to meet needs (Heintz et al. 2020). Consequently, PwD are less likely to receive care planning and many do not have access to specialized care (Martinsson et al. 2018). Often poorly understood and stigmatized, PwD and their families often struggle with social perceptions, inappropriate labelling, and difficult social interactions (Nguyen and Li 2020). This leads to a negative spiral of reluctance to integrate into society, resulting in reduced social support networks and increasing isolation. Most care for PwD is unpaid, coming from family and friends (Reyes et al. 2021). This extremely difficult role is associated with emotional and psychological problems such as anxiety, stress, and depression (Cheng 2017); physical health issues due to self-neglect as they prioritize the needs of the PWD over their own (Ortiz et al. 2009); financial burden (Liu et al. 2019); and problems with relationships and social isolation (Lindeza et al. 2020).

In contrast to those commercial organizations that have begun to recognize the opportunities within this large market, marketing academics have been slow. Few, if any, robust academic studies focus on this population have been published in the top marketing journals. A search of the top-20 in SJRs ranking list revealed only two papers in which appears the word 'dementia'. The first is a book review, the second (Oldenhof et al. 2013) examines value compromises among Dutch healthcare managers. Otherwise, the word 'dementia' is conspicuous by its absence in the top tier marketing journals.

The underlying reasons for marketing's almost total neglect of this population are unknown. However, in addition to being credible, the responsible research in marketing movement stresses that research "must devote more attention to developing new knowledge that benefits businesses and the broader society for the ultimate purpose of creating a better world" (Haenlein et al. 2022 p. 8). The purpose of this study is to examine the lived experiences of dementia patients and their caregivers as they navigate their consumer journey to provide research insights that can be used to create a better world for these consumers.

### **Consumer journeys**

Customer journey research has undoubtedly expanded understanding of customer experience (Lemon and Verhoef 2016). Journey scholarship also provides much useful information for practitioners (Edelman and Singer 2015). Studies into a range of journeys include retail (Herhausen et al. 2019), insurance (Hu & Tracogna 2020), membership subscriptions (George and Wakefield 2018), and tourism and leisure (Gyimóthy 2000). There is also increasing recognition that journeys comprise multiple channels and media. Consequently, studies examine cross-channel customer behavior, and consideration is now being given to showrooming and webrooming (Hu and Tracogna 2020). Limited numbers of studies examine services that include agents (Barwitz and Maas 2018; Li and Kannan 2014) in recognition that not all touchpoints are firm controlled (Yakhlef and Nordin 2021).

However, most research in this field concentrates on the customer rather than the consumer journey. The difference between a customer and a consumer is significant. Hamilton and Price (2019) explain that consumer roles are more extensive than customer roles, such as patient or parent as well as being a customer. A customer has a relationship with a firm (Betterncourt et al. 2022), so customer journeys map touchpoints between a customer and a brand. In contrast, a consumer must get a job done (Epp and Price 2011), so subsumed within a consumer journey are multiple customer journeys (Betterncourt et al. 2022). A consumer journey therefore provides richer and more extensive insights into the consumer experience than do customer journeys.

Increasingly, recognition is given to journeys are not traveled alone: giving rise to the need to consider significant others in journeys (Thomas et al. 2020). Hence, there is a call to consider 'traveling companions' (Hamilton et al. 2021). However, the journey literature has been relatively slow to address this, and it was only recently that Hamilton et al. (2021) proposed the social customer journey.

Finally, there is a relative paucity of studies that include vulnerable consumers. Vulnerability is defined from two perspectives: the biophysical/psychosocial model and the consumer vulnerability model. The former identifies vulnerable populations based on their biological or psychosocial status. This perspective views consumers who are poor, disabled, or from a legally recognized protected groups such as children as vulnerable (Leino et al. 2021). The alternative view is that vulnerability arises from marketplace powerlessness (Baker et al. 2005). From this viewpoint, consumers are vulnerable if they lack agency due to power imbalances in the marketplace, and as such any consumer can be vulnerable in certain contexts. Yet, few journey studies focus on vulnerable consumers. Rather, the bulk of research assumes agentic consumers who have free choice across the different phases of their journey.

We found only a handful of customer or consumer journey studies that focus on one or more of the gaps we identified. Though concentrating on agentic consumers, Gyimóthy (2000) recognized the significance of social experiences when she interviewed dyads about their tourism journeys. Taking a holistic view of the customer journey as one that incorporates transport and multiple retailers, Crosier and Handford (2012) advocated for more consideration of the needs of blind and partially sighted consumers. Two studies have examined the consumer journeys of patients. One investigated the ways in which patients create value throughout their cancer journeys (Trujillo Torres and DeBerry-Spence 2019), the other studied medication compliance among poor consumers attempting to comply with medication requirements for chronic hypertension (Nakata et al. 2019). We contribute to this literature by examining the consumer journeys of dementia patients and their families. The broad aim of the research is to understand the lived experiences of PwD and their family caregivers from diagnosis through accessing and consuming any service designed to help them.

## Methods

# **Ethics**

Given the biophysical vulnerability of this population, ethical issues took on elevated scrutiny. University ethical approval entailed detailed written documents and the research team made an in-person defense of the research to the University's Ethics Committee. All documentation confirmed that the research was opt-in, totally voluntary, anonymous, and in confidence. All participants were able to give informed consent.

### **Recruitment procedure**

The research is a collaboration between the research team and a hospice unit that until recently has focused on palliative care. Recently, in recognition of marketplace needs, the hospice has begun to offer a 6-week course for people caring for dementia patients. During the sessions, PwD are looked after by hospice staff and volunteers, with singing, 'love to move' sessions (chair-based exercises), and craft classes. Clearly, from this perspective, consumers are both PwD and their caregivers. Advertisements detailing the study were placed in the hospice and these provided details of how to participate.

### Data collection

Participants were given a choice of data collection settings. Some opted for a quiet room in the hospice, some preferred the research team to visit them in their own homes, and a few chose Zoom. With permission, interviews were recorded and transcribed verbatim.

To aid systematic data collection, we used the first three sets of touchpoints from the Trajectory Touchpoint Technique (TTT) (Sudbury-Riley et al. 2020). These are illustrated in Figure 1. Touchpoints can be physical, sensorial, symbolic, and social and incorporate consumer expectations, barriers, motivators, feelings, and emotions (De Keyser et al. 2015). The touchpoint images are presented as rich cartoon pictures, which are particularly appropriate for complex research situations (Cristancho et al. 2015). The range of touchpoints enable rich data collection pertaining to multiple forces and interactions and have been shown to capture and illuminate influences that may otherwise have remained hidden (Sudbury-Riley et al. 2020).

Each set of touchpoints relate to service customer journey stage. In our case, stage 1 comprises diagnosis; stage 2 is the post-diagnosis period where people seek information and access to services; and stage 3 comprises service experiences. The touchpoint images act as an aide memoir, and participants are free to choose all, none, or some of them. They are also free to talk about any touchpoints they found important that were not contained in the TTT. We stressed that the aim of the conversation was to capture their story, viewing their narrative as a journey from the experiences leading up to diagnosis, through to the present day.

#### Sample

We reached saturation at around 30 narratives. The final sample (n = 33) comprises 5 PwD while the rest are family caregivers. All White British with most of higher socioeconomic statuses, 45% of participants are male.

#### Data Analysis

We used manual thematic analysis to analyze the data, following the stages and processes suggested by Braun and Clarke (2006).

### Results

The data is rich, thick, and extensive. Word limits necessitate only a snapshot of results here. For brevity, we present some major themes, and Table 1 provides verbatim quotes to illustrate these themes.

# Stage 1: Diagnosis

The beginning of consumer journeys were often characterized by significant delays. We found four reasons for this. First, the PwD did not initiate the journey. Rather, it was relatives who first noticed signs of dementia. A process of watching and waiting then tended to follow, during which time people were reluctant to fully admit that there was a problem. Second, because the PwD did not always acknowledge a problem, many journeys were further delayed. This reluctance is typical for so-called negative services (Berry and Bendapudi 2007), which exist to fix people or things, often when the problems are serious and non-routine (Morgan and Rao 2006).

A third underlying reason for delays at this stage was a perception that medical professionals did not properly listen to family members, often contradicting caregiver insights and not sufficiently valuing their opinions and experiences. A clear power imbalance between provider and service user led to significant delays to diagnosis, and to feelings of frustration and vulnerability among caregivers as they struggled alone. Consumer vulnerability can arise from knowledge imbalances (Baker et al. 2005). In this situation, while clinical staff had the medical knowledge, it was the caregivers who had knowledge of the ways in which the PwD had changed in terms of cognition and behavior. Yet, the medical knowledge overruled this, with professional power causing further delays.

Finally, timing was an issue for many, because their initial journey coincided with COVID-19. Health services struggled to function (BMA 2022) and many doctor's

appointments moved to telephone consultations which made diagnosis more difficult. Additionally, there were delays to the MRI scans needed. The impact on this situation was severe, both in terms of slowing down journey progress towards getting help for the PwD, and for the caregiver who began to feel extra isolation and anxiety as their family member's condition worsened.

# Stage 2: Seeking Access

Post-diagnosis marked a shift to stage 2 in the consumer journey, where people began to seek information and access to services designed to help. For many caregivers, feelings of isolation and being afraid marked this stage. Typical to consumer journeys are roles outside that of a customer (Hamilton and Price 2019). Fear among participants came partly from contemplation of new role expectations (or demands), as Keith's quote (table 1 and the title of this paper) reflects. The complexity of the service system they needed to access, comprising myriad providers from health, social care, and the charity sector added to a sense of bewilderment among many. A lack of coordination between organizations also added to delays at this journey stage.

Participants had varied levels of success in seeking further information about the condition and support services on offer. Feelings of being overwhelmed were commonplace. Sometimes this was due to the lack of precision pertaining to the diagnosis. With hundreds of different forms of dementia that each manifest differently (Dementia UK 2023), people struggled to access information relating to their specific diagnosis. Being overwhelmed often followed from information overload, due to too much information and therefore too much noise in the communications process.

While some managed to conduct their own extensive research, others, like 87-year-old Rose, lacked the digital literacy to be able to do this. Here is an example of contextual consumer vulnerability (Baker et al. 2005), caused by the consumer having insufficient resources (in the form of skills and knowledge) to search for the information she required. Indeed, receiving useful information about services that could help often came from serendipitous conversations or from word-of-mouth communications with people within existing networks, rather than official channels. These information-related problems continued and led to further delays to referral to appropriate services. Often, the focus in journey literature is solely on firm-controlled touchpoints (Lemon and Verhoef 2016). Here we have important examples of consumer-to-consumer touchpoints, which are only just being recognized in the consumer journey literature (Yakhlef and Nordin 2021).

As with any taboo, misconceptions pertaining to hospice abound in society (Cagle et al 2016). People assume hospice is solely for cancer patients, or solely for people who are dying. We identified evidence of these misconceptions among PwD and their families, which led to further delays in the journey to access support.

### Stage 3: Service Experiences

Surprise and relief were typical of experiences when people did access the hospice for the caregiver's course. The misconceptions of hospice, so prevalent among the population (Cagle et al 2016) were banished when people experienced the peaceful and tranquil servicescape, and relief at the professionalism and high-quality care their relatives received from front-line staff.

Peer support emerged as a key benefit of the caregiver course and other social groups, helping to mitigate experiences of isolation and being cut off from existing social ties. Our findings support those in the clinical literature pertaining to the often-unmet social needs of caregivers (Lindeza et al. 2020). Often, connections were maintained after courses ended, providing a much-needed longer-term source of mutual support.

Multiple participants described issues with connectedness, coordination, and communication between different services. Such problems are typical to complex service systems comprising multiple agencies (Ellis et al. 2017). Coordination problems impacted the

consumer journey, causing delays and frustrations. This situation placed even greater pressure on carers and led to inconsistencies in treatment received.

Consistent with clinical literatures (Heintz et al. 2020; Martinsson et al. 2018), we identified major gaps in service provision, primarily relating to the wider health and social care system. Caregiver narratives repeatedly highlighted the need for a single point of contact: someone they could turn to throughout the entirety of their journey, who would help them navigate service systems, face challenges as they arose, and help with future planning. Finally, and supporting findings reflected in the care literature (Hunter-Jones et al. 2023), there is a desperate unfulfilled need for respite for caregivers. Caregivers reported feeling exhausted, burnt-out, and for some, feelings of resentment arose.

### **Discussion and Conclusions**

We make several contributions. To the marketing literature in general, we provide rare empirical insights into the consumer experiences of an overlooked population. If we, the marketing academe, are to make the meaningful progress advocated by the responsible research in marketing movement (Haenlein et al. 2022), we need to begin to seek out underserved and in-need populations, not matter how hard-to-reach. This small-scale study is testimony that our marketing community is equipped to do so.

We make several contributions to the theoretical consumer journey literature. Our work enriches consumer journey knowledge by expanding the relatively tiny number of empirical studies pertaining to difficult consumer journeys which incorporate roles that go beyond that of consumer (Nakata et al. 2019 Trujillo Torres and DeBerry-Spence 2019). We spotlight the ways in which these roles (in our case, caregiver) can be frightening and unwelcome, and certainly many people are ill equipped for them. Yet, we found consumers to perceive a presumption among service providers that they can make this role transition seamlessly and without sufficient help. This was not a situation reflected in the lived experiences in our narratives: people found this role transition extremely difficult.

We provide a rare examination of a consumer journey that transcends usual path-topurchase consumption journeys upon which much journey research is based (Lemon and Verhoef 2016). We show that sometimes a consumer journey can be arduous and external systems and processes can often cause delays which have profoundly negative impacts on consumers. Our work therefore contributes to the nascent research on consumer vulnerability (Baker et al. 2005). We spotlight a type of secondary vulnerability (Leino et al. 2021) throughout a consumer journey, which occurs when the vulnerability of the primary consumer impacts the agency of others in their social network. We show that even though caregivers are not vulnerable in the biophysical sense, they feel powerless in the face on a negative service that is complex and difficult to understand. Insufficient information, provided via ineffective channels, added to feelings of helplessness and vulnerability.

Finally, our work enriches knowledge pertaining to traveling companions in consumer journeys. While not reflective of reality, the journey literature usually considers single consumers (Hamilton et al. 2021; Thomas et al. 2020). In our case, we found that it is the traveling companion who interacts with gatekeepers and various providers in order to move the journey along for a primary consumer. We also identified a range of unmet needs for traveling companions themselves. Our results therefore complement and extend previous work by supporting recent research on the service inclusion needs of secondary customers (Leino et al. 2021). Too often, service design overlooks the needs of secondary customers. From a journey perspective, we spotlight the ways in which traveling companions try to navigate the journey on behalf of the primary consumer and navigate their own journey as they attempt to cope with role changes. In our case, this role transition comprised spouse or adult child to caregiver. Our work has several implications for practice. Providers of dementia services need to work with their consumers to design information that is useful and accessible to their target market. Part of this information strategy needs to recognize that not all people within this segment are digitally literate. Those working in individual organizations need to realize that they are part of a network, and consumers often have difficulty navigating a complex and unfamiliar system. Peer-to-peer support was greatly valued among our sample; hence we suggest that providers should find ways to encourage and facilitate such networks among their consumers. We also suggest there is a great need for a 'journey buddy': a single point of call that people can turn to when the journey gets particularly difficult. Finally, there is a very great need for respite services. There are clear opportunities for the leisure industry here. Dementia is set to increase significantly in the coming years (WHO 2023), so the current market, which is far from unsubstantial, will grow. There are myriad unmet needs, and a desperation among many for more services to help them. We suggest there are myriad opportunities for organizations to begin to better meet these needs.

	Initial Journey Stage: Diagnosis
Delays in diagn	
Reluctance	"By now it was November. I mean this had taken a year plus, we're going into
	our second year" (Francis, 70, caregiver to husband)
Denial	"It's not so easy for me, taking phone calls and talking about Jim and Jim's
	condition when Jim's there. I just can't do that to him because I'm just
	reminding him that there's a problem because quite a lot of the time, he's not
	aware of it, and I think that's a nice way to be for both of us. I wear hearing
	aids, so I have to put the phone on speaker phone" (Catherine, 78, carer to her
	husband).
Power	"So [we] went to the doctor's and I think that's where I kind of did find a
imbalance	frustration. Because nobody really wanted to know They all said, "Well he's
	fine, you know, there's not a problem at all." And there is me back at home
	<i>thinking, I know it's a problem!</i> " (Gayle, 66, caregiver to husband)
COVID-19	"But then you know we were getting towards the end of 2019 and of course we
	then got Covid. So, we were then essentially just left. And things did progress
	and get worse. I found that really, really difficultAnd nobody really seemed to
	want to know at that stage" (Harry, 77, caregiver to wife).
	Journey Stage 2: Seeking Access
Gaps in support	
Feeling alone	"I remember him [doctor] telling me I'd got to learn to behave like a saint. You
	know, we all have- He didn't say, "Well, it's going to be tough," etc, "you've
	just got to behave like a saint". That wasn't very helpful, no. Not very
	impressed with the service from the [memory] clinic. It seemed to be a case of
	go on this medication, go away, and live with it" (Keith, 82, caregiver to his
	wife).
Problems with	"So we're getting around to 12 months since initial diagnosis kind of thing, or
follow up	whatever. And it was then that I rang Social Services. I said, "You sent a fellow
tonow up	around 11 months ago. What came out of that?" "Oh, oh, oh yes, there is a
	report." Well, I never saw itSo whose benefit was that for?" (Rachel, 53,
	caregiver to her father)
Information ava	
Imprecise	<i>"There are 200 different types of dementia. I don't know which one it was, or</i>
diagnosis	even if it was or what. So, it doesn't really help" (PwD).
Information	"The thing that I felt was the fact that everybody was really keen to provide you
	with information. I was overwhelmed with information. But nobody did anything
overload	<i>practical</i> " (Barbara, 84, caregiver to husband)
Digital literagy	<i>"I think it would be better if somebody would come out and speak to you.</i>
Digital literacy	
	Because I can't use a computer. So, I can't do the internet or anything like that.
Referral	So, I find it difficult to contact people" (Rose, 87, caregiver to husband)
Serendipity	"Next door, but one, my neighbours, she worked with dementia. And her
Serendipity	husband still does. So, in desperation, because I just didn't know which way to
	turn, I went to them. They're very goodVery nice neighbours. And she gave me
Word-of-mouth	<i>a list of charities that I could ring</i> " (Madeline, 68, caregiver to husband)
	"My daughter, who is a pharmacy technician, she works at the doctor's surgery, and she had a word with the ladies there and they sent me a book they
	surgeryand she had a word with the ladies there and they sent me a book, they
	sent me piles of leaflets all about it and they got me in touch with a club which
Missonsertie	<i>we go to every other Tuesday</i> " (Dawn, 70, caregiver to husband)
Misconceptions	"I must admit I do tend to think of the hospice as basically being, you know,
about hospice	cancerSo I'm probably guilty of notmaybe looking"
	(Chris, 73, caregiver to his wife)

 Table 1: Verbatim Quotes Illustrating Key Themes

	Journey Stage 3: Service Experiences	
Service delivery		
Surprise & relief	"It's great. And the people here are so kindI can't speak highly enough of them." (Nerson, 78, Pwp)	
	them" (Noreen, 78, PwD)	
Peer support	"I'm quite happy with it how it is because I just like being with people and I like listening to people's stories about their life and what they did as a job, I find it really interesting" (Miles, 74, PwD).	
Coordination between services	"There's no looking at the situation holistically. It's just pragmatically looking at the narrow, that function of that person at that requirement. It's as narrow and as blinkered as possible. With one individual who is so general and then everybody I have come across with networking with those family members that have got dementia, everybody says the same. GPs [family doctors] do not	
	understand dementia" (Irene, 36, caregiver to her mother).	
Gaps in service provision		
Single point of contact	"There is that missing link of who can I phone when things aren't going quite right. Who can I ring when – have you come across this situation before? You know, from another a client, what have they done?" (Emma, 77, caregiver to her husband)	
Respite needs	"I need to make an appointment to have my eyes tested because I'm well overdue that, but unless I arrange it, say to my daughter, could you be available in the daytime, etcetera, you know, it's just things like that, it's just not easy" (Len, 84, Caregiver to his wife).	



Figure 1. Trajectory Touchpoint Technique Images

# References

- Alzheimer's Association (2023), "Alzheimer's Disease Facts and Figures". Chicago: Alzheimer's Association.
- Alzheimer's Society (2023), "Alzheimer's Society Support", (accessed May 22, 2023), https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia
- Baker, Stacey. M., James W. Gentry, and Terri L. Rittenburg (2005), "Building Understanding of the Domain of Consumer Vulnerability," *Journal of Macromarketing*, 25(2), 1-12.
- Barwitz, Niklas, and Peter Maas (2018), Understanding the Omnichannel Customer Journey: Determinants of Interaction Choice. *Journal of Interactive Marketing*, 43, 116–133.
- Berry, Leonard L. and Neeli Bendapudi (2007), "Health Care: A Fertile Field for Service Research. *Journal of Service Research*, 10, 111-122.
- Bettencourt, Lance A., Colleen Harmeling, Yashoda Bhagwat-Rana, and Mark B. Houston (2022), "Consumer Job Journeys", *Journal of Service Research*, 25(3), 347-370.
- BMA (2022), "COVID-19: Impact of the Pandemic on Healthcare Delivery", (accessed May 20, 2023), <u>https://www.bma.org.uk/advice-and-support/covid-19/what-the-bma-is-doing/covid-19-impact-of-the-pandemic-on-healthcare-delivery</u>

Bourgeois, Michelle S. (2014). *Memory and communication aids for people with dementia*. Illinois: Health Professions Press.

- Braun, Virginia, and Victoria Clarke (2006) "Using Thematic Analysis in Psychology", *Qualitative Research in Psychology*, 3(2), 77–101.
- Cagle, John G., Daniel J. Van Dussen, Krystal L. Culler, et al. (2016), Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. *American Journal of Hospice and Palliative Medicine*, 33(1), 27-33.
- Cheng, Sheung-Tak (2017), "Dementia Caregiver Burden: a Research Update and Critical Analysis. *Current Psychiatry Reports*, 19, 64, doi: 10.1007/s11920-017-0818-2.
- Clatworthy, Simon (2011), "Service Innovation through Touchpoints: Development of an Innovation Toolkit for the First Stages of New Service Development," *International Journal of Design*, 5 (2), 15-28.
- Cristancho Sayra, Susan Bidinosti, Lorelei Lingard, Richard Novick, Michael Ott, and Tom Forbes (2015), "Seeing in Different Ways: Introducing "Rich Pictures" in the Study of Expert Judgment. *Qualitative Health Research*, 25(5), 713–725.
- Crosier, Adam, and Alison Handford (2012), "Customer Journey Mapping as an Advocacy Tool for Disabled People: A Case Study. *Social Marketing Quarterly*, 18(1), 67-76.
- De Keyser, Arne., Katherine A. Lemon, Philipp Klaus, and Timothy L. Keiningham (2015), "A framework for Understanding and Managing the Customer Experience. *MSI Working Paper* No. 15-121. Cambridge, MA: Marketing Science Institute.
- Dementia UK (2023), "Types of Dementia," (accessed May 1 2023), https://www.dementiauk.org/about-dementia/types-of-dementia/
- Edelman, David C., and Marc Singer (2015), "Competing on Customer Journeys," *Harvard Business Review*, 93, 88–100.
- Ellis, Beverley, and Stuart Herbert (2011), "Complex adaptive systems (CAS): An overview of key elements, characteristics, and application to management theory," *Informatics in Primary Care*, 19, 33-37.
- Epp, Amber M., and Linda Price (2011), "Designing Solutions Around Customer Network Identity Goals," *Journal of Marketing*, 75, 36-54.

- George, Morris, and Kirk L. Wakefield (2018), "Modeling the Consumer Journey for Membership Services," *Journal of Services Marketing*, 32, 113–125.
- Gibson, Grant, Lisa Newton, Gary Pritchard, Tracy Finch, Katie Brittain, and Louise Robinson, (2016), "The Provision of Assistive Technology Products and Services for People With Dementia in The United Kingdom," *Dementia*, 15(4), 681-701.
- Gyimóthy, Szilvia (2000), "Odysseys: Analyzing Service Journeys from the Customer's Perspective. *Managing Service Quality*, 10(6), 389-396.
- Haenlein, Michael, Mary Jo Bitner, Ajay Kohli, Katherine N. Lemon, and David J. Reibstein (2022), "Responsible Research in Marketing," *Journal of the Academy of Marketing Science*, 50, 8–12.
- Hamilton, Rebecca (2016), "Consumer-Based Strategy: Using Multiple Methods to Generate
- Consumer Insights that Inform Strategy," *Journal of the Academy of Marketing Science*, 44, 281-285.
- Hamilton, Rebecca W., Linda L. Price (2019), "Consumer Journeys: Developing Consumer-Based Strategy," *Journal of the Academy of Marketing Science*, 47, 187–191.
- Hamilton, Ryan, Rosellina Ferraro, Kelly L. Haws, and Anirban Mukhopadhyay (2021), "Traveling with Companions: The Social Customer Journey. *Journal of Marketing*, 85(1), 68-92.
- Heintz, Hannah, Patrick Monette, Gary Epstein-Lubow, Lorie Smith, Susan Rowlett, and Brent P. Forester (2020), "Emerging Collaborative Care Models for Dementia Care in the Primary Care Setting: A Narrative Review," *The American Journal of Geriatric Psychiatry*, 28(3), 320-330.
- Herhausen, Denis, Kristina Kleinlercher, Peter C. Verhoef, Oliver Emrich, and Thomas Rudolph (2019), "Loyalty Formation for Different Customer Journey Segments," *Journal of Retailing*, 95(3), 9-29.
- Hu, Tun I., Andrea Tracogna (2020), "Multichannel Customer Journeys and their Determinants," *Journal of Retailing and Consumer Services*, 54, DOI: 10.1016/j.jretconser.2019.102022
- Hunter-Jones, Philippa, Lynn Sudbury-Riley, Jade Chan, and Ahmed Al-Abdin (2023), "Barriers to Participation in Tourism Linked Respite Care," *Annals of Tourism Research*, 98, 103508.
- Hurd, Michael D., Paco Martorell, Adeline Delavande, Kathleen J. Mullen, and Kenneth M. Langa (2013), "Monetary Costs of Dementia in the United States," *New England Journal of Medicine*, 368, 1326-1334.
- Leino, Henna M., Leila Hurmerinta, and Birgitta Sandberg (2021), "Balancing Service Inclusion for Primary and Secondary Customers Experiencing Vulnerabilities," *Journal of Services Marketing*, 35, 692-705.
- Lemon, Katherine N., and Peter C. Verhoef (2016), "Understanding Customer Experience Throughout the Customer Journey," *Journal of Marketing*, 80, 69–96.
- Li, Hongshuang and P. K.Kannan (2014), "Attributing Conversions in a Multichannel Online Marketing Environment," *Journal of Marketing Research*, 51, 40–56.
- Lindeza, Patricia, Mário Rodrigues, João Costa, Manuela Guerreiro, and Mario Miguel Rosa (2020), "Impact of Dementia on Informal Care: A Systematic Review of Family Caregivers' Perceptions," *BMJ Supportive & Palliative Care*, doi:10.1136/bmjspcare-2020-002242

- Liu, Yin, Malinda Dokos, Elizabeth B. Fauth, Yoon G. Lee, and Steven H. Zarit (2019),
  "Financial Strain, Employment, and Role Captivity and Overload Over Time Among Dementia Family Caregivers," *The Gerontologist*, 17, 59(5), e512-e520.
- Martinsson, Lisa, Staffan Lundstrom, and Johan Sundelof (2018), "Quality of End-of-life Care in Patients with Dementia Compared to Patients with Cancer: A populationbased Register Study," *PLoS ONE* 13(7): e0201051.
- Morgan, Ivor and Jay Rao (2006), "Growing Negative Services.," *MIT Sloan Management Review*, 47(3), 69-74.
- Nguyen, Trang and Xiaoming Li (2020), "Understanding Public-Stigma and Self-Stigma in the Context of Dementia: A Systematic Review of the Global Literature," *Dementia*, 19(2), 141-181.
- Oldenhof, Lieke, Jeroen Postma, and Kim Putters (2013), "On Justification Work: How Compromising Enables Public Managers to Deal with Conflicting Values," *Public Administration Review*, 74, 52-63
- Ortiz, Natalia, Ruth Lamdan, Shaneek Johnson, and Aihem Korbage (2009), "Caregiver Status: A Potential Risk Factor for Extreme Self-neglect," *Psychosomatics*, 50,166-168.
- Reyes, Adriana M, Johanna Thunell, and Julie Zissimopoulos (2020), "Addressing the Diverse Needs of Unpaid Caregivers Through New Health-Care Policy Opportunities," *The Public Policy & Aging Report*, 21 (31), 19-23.
- Sudbury-Riley, Lynn, Philippa Hunter-Jones, Ahmed Al-Abdin, Daniel Lewin and Vic M. Naraine (2020), "The Trajectory Touch-Point Technique," *Journal of Service Research*, 23(2), 229-251.
- Thomas, Tandy C., Amber M. Epp, and Linda L. Price (2020). Journeying together: Aligning retailer and service provider roles with collective consumer practices. *Journal of Retailing*, 96, 9-24.
- Trujillo Torres, L., & DeBerry-Spence, B. (2019). Consumer valorization strategies in traumatic experiences. Journal of the Academy of Marketing Science, 47, 516–531.
- Trujillo Torres, Lez and Benét DeBerry-Spence (2019), "Consumer Valorization Strategies in Traumatic Experiences. *Journal of the Academy of Marketing Science*, 47, 516–531.
- Tueanrat, Yanika, Savvas Papagiannidis, and Eleftherios Alamanos (2021), "Going on a Journey: A Review of the Customer Journey Literature," *Journal of Business Research*, 125, 336-353.
- United Nations (2019), "World Population Ageing 2020 Highlights," (accessed April 19 2023),

https://www.un.org/development/desa/pd/news/world-population-ageing-2020highlights

- World Health Organization (2012), "Dementia: A Public Health Priority," (accessed February 14 2023), <u>https://www.who.int/publications/i/item/dementia-a-public-health-priority</u>
- World Health Organization (2023), "Dementia", (accessed February 14 2023), <u>https://www.who.int/news-room/fact-sheets/detail/dementia</u>
- Wilkinson, Tim, Christian Schnier, Kathryn Bush et al. (2019), "Identifying Dementia Outcomes in UK Biobank: A Validation Study of Primary Care, Hospital Admissions and Mortality Data. *European Journal of Epidemiology*, 34, 557–565.

- Yakhlef, Ali and Fredrik Nordin (2021), "Effects of Firm Presence in Customer-Owned Touch Points: A Self-determination Perspective," *Journal of Business Research*, 130, 473-481.
- Zomerdijk, Leonieke G. and Christopher A. Voss (2010), "Service Design for Experience Centric Services," *Journal of Service Research*, 13(1), 67–82.