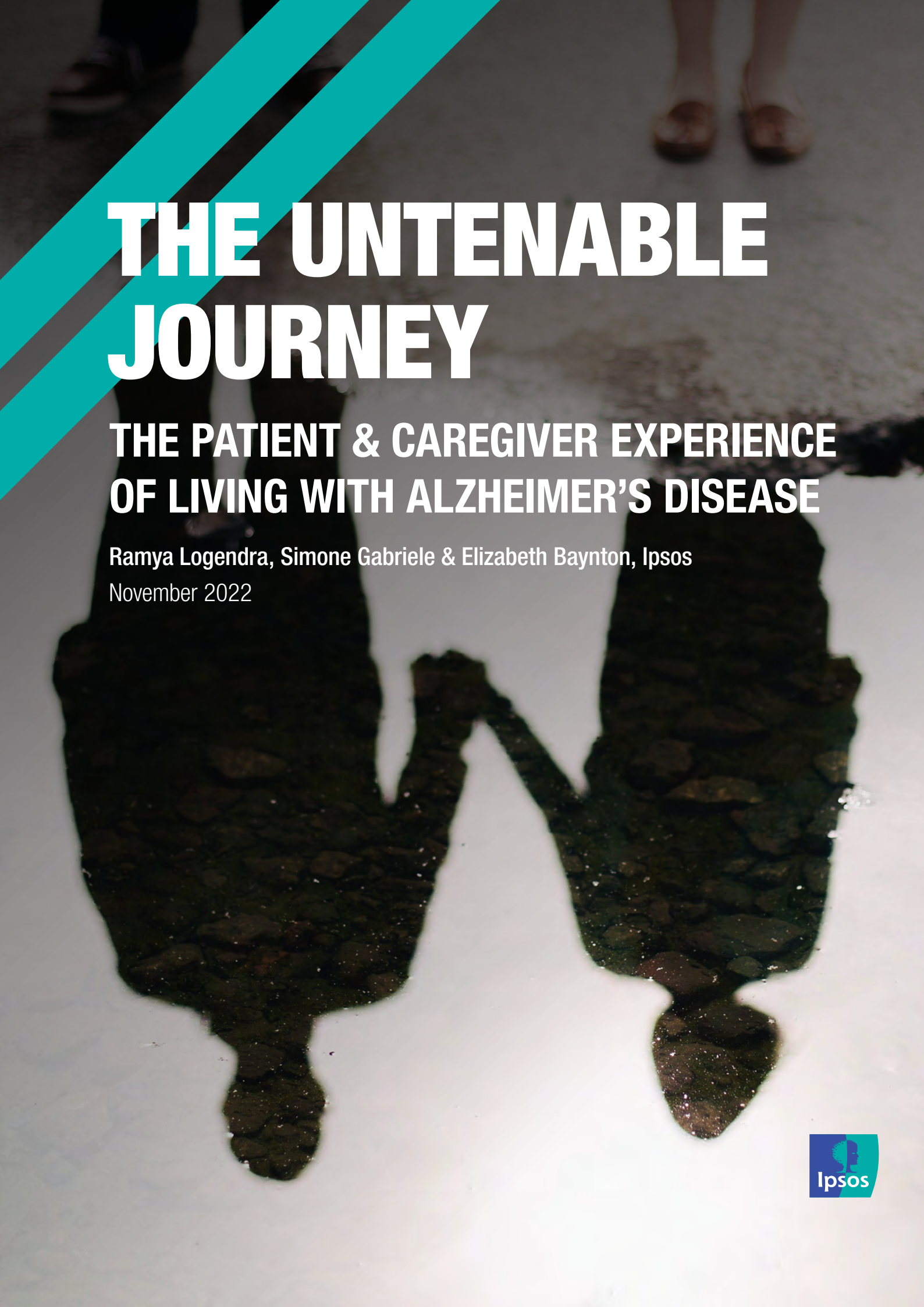

THE UNTENABLE JOURNEY

THE PATIENT & CAREGIVER EXPERIENCE OF LIVING WITH ALZHEIMER'S DISEASE

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November 2022

Ipsos

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The patient & caregiver experience of living with Alzheimer's Disease

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NOVEMBER 2022

One simplistic definition of Alzheimer's Disease is "*a brain disease that causes problems with memory, thinking and behaviour*"[1]. When delving into the patient and caregiver experience of living with this condition, from symptoms and diagnosis through to treatment and support, the journey is far from simple. Aside from the challenge of accessing treatment, denial, misdiagnosis and the long-term emotional impact for all involved all factor into the complexity of the journey.

For this article, we used Ipsos' social intelligence platform, Synthesio, to explore the online discussion from Alzheimer's patients and caregivers. With insights taken from over 900,000 social media and forum posts across nine countries* we look to understand the toll this condition takes and identify potential areas in which the pharmaceutical industry may be able to support the Alzheimer's community.

*See *'About the Research'* for further details

INTRODUCTION

There is currently no cure for Alzheimer's and, up until last year, there were only treatments available that may help treat symptoms[1]. In 2021, the first treatment to address the underlying biology of Alzheimer's Disease was approved by the FDA in the US[2] (its marketing authorisation application was withdrawn in the EU earlier in 2022[3]). Now the developmental pipeline is rich with potential treatments for disease modification, cognitive enhancement and managing behavioural and neuropsychiatric symptoms[4]. Despite recently reported clinical trial challenges for some companies in this market, the potential for these treatments in development to stop or significantly delay the progression of Alzheimer's is vast.

This is welcome news, but people living with and caring for others with this condition are being affected now and in multi-faceted ways.

We have broken this down into four key stages of the Alzheimer's journey pathway, highlighting the emotional, logistical and financial frustrations experienced by those involved, with a view to putting the spotlight on vital unmet needs.

1. PRE-DIAGNOSIS

One of our primary findings from the social intelligence research relates to the challenges that exist in getting an Alzheimer's diagnosis. The effectiveness of some of the disease modifying innovations in the late-stage pipeline relies heavily on early detection, accurate diagnosis and early treatment – so overcoming these challenges is paramount.

The obvious first step to diagnosis of any condition is recognition of symptoms. Our research from the patient/caregiver perspective suggests limited knowledge of symptoms on their own part but, in the opinion of some, among healthcare professionals (HCPs) too. To compound this, there are some symptoms which are perceived as general signs of ageing, e.g., forgetfulness, repeating things. This gives rise to an initial unmet need to be addressed – educating the wider population about signs to look out for. Findings from our study highlighted that the symptoms which did prompt caregivers or patients to contact HCPs included emotional changes, communication problems, memory loss, cognitive decline (such as difficulty completing daily tasks), headaches and pressure behind the eyes.

Sadly, the difficulty of recognising symptoms can be further compounded by denial and masking. Our analysis highlighted instances in which both patients and those close to them may know 'something is wrong' but do not want to admit it. Factors driving this appear to include fear of the future, fear of ruining retirement plans and shame in admitting something is wrong.

Even the concept of denial has its own idiosyncrasies. What can be perceived as denial or stubbornness may actually be a genuine lack of awareness that anything is wrong. Clinically, it is termed anosognosia, which is the inability to understand and accept one's condition. This can be a symptom of Alzheimer's and some social media posts indicated a need to ensure that HCPs understand this and, importantly, communicate it to caregivers. Recognition and highlighting of anosognosia in educational material is therefore a worthy side note.

2. TESTING

A hurdle we identified that extends from pre-diagnosis to diagnosis is resistance – to seeking help, seeing a doctor, getting diagnostic tests, and more.

On top of this human element are practical difficulties. There is no one test to diagnose Alzheimer's but a battery of them, designed to also rule out other conditions; a test with 100% accuracy is therefore currently not available. If you are already faced with resistance from a patient to get tested, how do you persuade them to get multiple tests?

In addition, we noted comments from people in regions where healthcare insurance can form another barrier. Mentions in the US highlighted reluctance to use certain tests as they were not covered by their insurance providers, or that a positive Alzheimer's genetic test in itself would invalidate their insurance. In Spain, we noted mentions of family members being reluctant to receive genetic testing to understand any potential hereditary risks of the disease as it could affect eligibility for long term care insurance.

3. DIAGNOSIS

Receiving a diagnosis is not always a straightforward process, in some people's experience. Based on the aforementioned testing process, the road to diagnosis can be lengthy and – due to a lack of absolute testing accuracy – can lead to initial misdiagnosis. Sometimes, a delay has already been experienced in the referral process between the primary care practitioner (PCP) and specialist. This can mean that by the time the diagnosis is confirmed, some patients have already progressed to the mid-stage of the disease, narrowing treatment options. Additionally, some caregivers/patients alluded to a reluctance on the part of physicians to admit to an Alzheimer's diagnosis – it was suggested that some neurologists feel that giving a person a terminal diagnosis when they don't have the cognitive capacity to process it is unnecessary and unhelpful. In our research we perceived a sense of frustration by some that health systems are failing Alzheimer's patients, as they are not always assessed and diagnosed correctly or in a timely way, or giving a diagnosis is avoided altogether.

The receipt of a diagnosis is a key point at which support and information is highly sought after. In our research we saw that, shortly after diagnosis, loved ones typically reach out on online forums to ask where they can find more information about Alzheimer's and what kind of care their loved one can access. People reported being signposted to 'Care Consultants' provided by the Alzheimer's Association, who are able to answer questions about Alzheimer's and provide counselling for caregivers. Importantly for many, their services are provided free of charge.

Whilst the entire journey benefits from an empathetic ear, we registered key emotions in our research pertaining to the diagnosis stage that lend themselves to a particularly human response: uncertainty, sadness, anger, guilt, fear and relief. The point of diagnosis can be a key touchpoint where industry may be able to offer additional help - for example, with support tools for caregivers – ensuring, of course, that communications convey the empathy and understanding that the recipients need at this stage.

WE PERCEIVED A SENSE OF FRUSTRATION THAT HEALTH SYSTEMS ARE FAILING ALZHEIMER'S PATIENTS; THEY ARE NOT ALWAYS ASSESSED CORRECTLY OR IN A TIMELY WAY, OR A DIAGNOSIS IS AVOIDED ALTOGETHER.

4. DISEASE MANAGEMENT

In the early stages of living with and managing this condition, it is understandable that there is a lot of emotion to process and information to digest. Our research noted a particular unmet need at this stage for professional guidance and support for caregivers dealing with their loved ones' psychological experience. Changes in the patient's behaviour can be challenging, and progression can be fast, making it harder for caregivers or loved ones to cope. Support is typically found on online forums, particularly emotional and practical help in dealing with the disease, including the daily challenges and difficulties of living with Alzheimer's. According to some contributors, much of the care is also pushed to social care departments, which often lack the resource to be able to support families adequately. This highlights the need for more 'joined up' support and communication across the healthcare system.

Some who have been through the diagnosis process advise on the need to act quickly to ensure the right specialists are seen and the right care plan is put in place – this is especially true for those diagnosed with early onset Alzheimer's. Of particular note was some advice coming out of the US element of the research to assemble a cache of niche specialists, such as geriatricians, geriatric psychologists and attorneys.

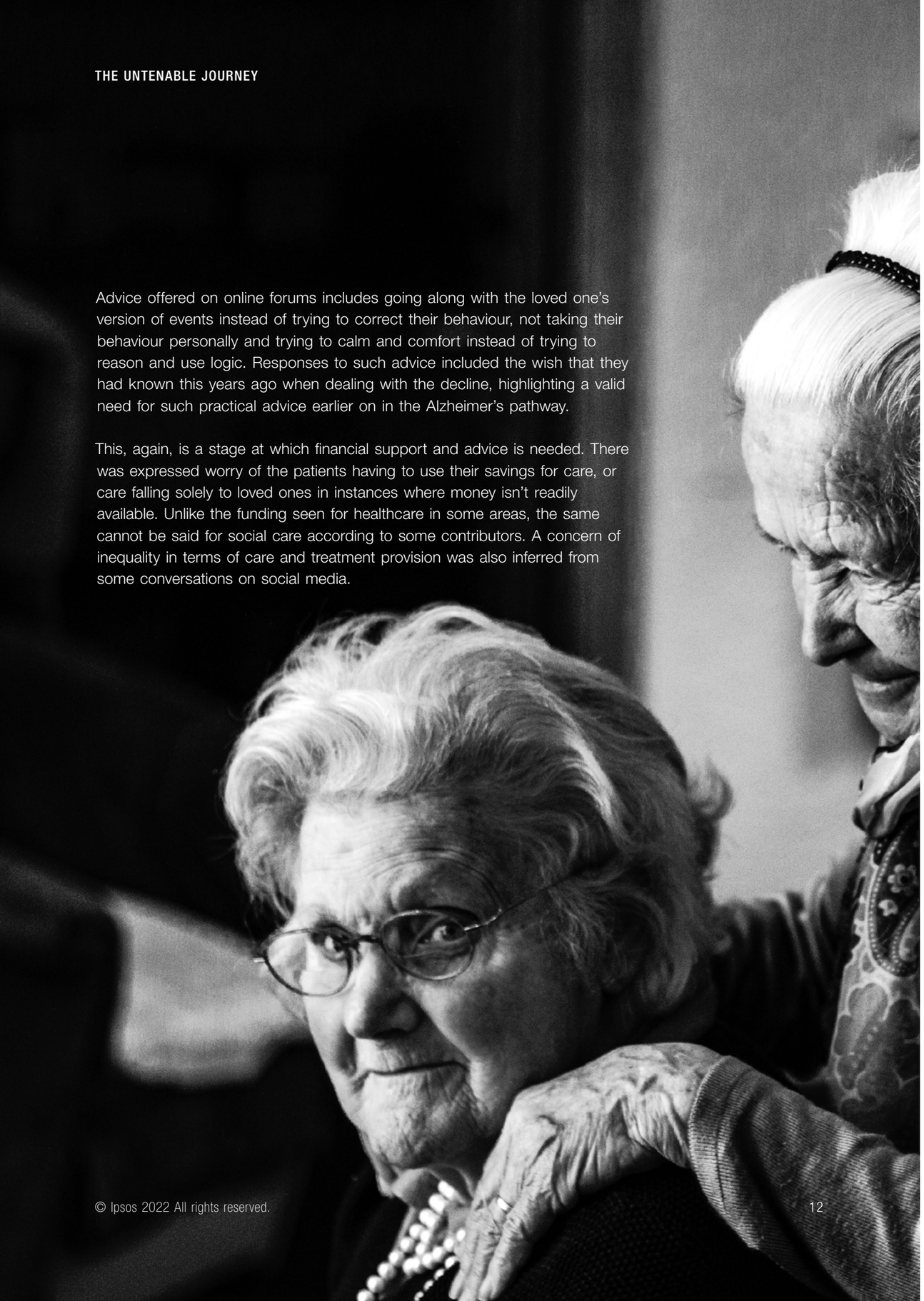
This is also a stage at which patients can get anxious and appear uncooperative, and the thought of taking their medication or attending doctor appointments can lead to distress and a refusal to go, providing a further pain point for both patients and caregivers. This is an area where the pharmaceutical industry may consider providing additional support to both parties, to help facilitate treatment adherence as new products enter the market that may require regular infusions and monitoring.

The more established, or end phase, of disease management can be particularly gruelling. For the patient, severe memory loss and lack of physical control have set in; for the caregivers, their mental health can be suffering as a result of becoming a carer at the expense of their own self-care. Much of the discussion online is linked to coping mechanisms: how they manage to deal with the often-difficult situations and how they deal with the often-childlike behaviour. Conversation can focus more on sharing stories, giving and receiving advice, and, in essence, 'letting off steam' about their daily challenges and struggles as a caregiver.

FOR THE PATIENT, SEVERE MEMORY LOSS AND LACK OF PHYSICAL CONTROL HAVE SET IN; FOR THE CAREGIVERS, THEIR MENTAL HEALTH CAN BE SUFFERING AS A RESULT OF BECOMING A CARER AT THE EXPENSE OF THEIR OWN SELF-CARE.

Advice offered on online forums includes going along with the loved one's version of events instead of trying to correct their behaviour, not taking their behaviour personally and trying to calm and comfort instead of trying to reason and use logic. Responses to such advice included the wish that they had known this years ago when dealing with the decline, highlighting a valid need for such practical advice earlier on in the Alzheimer's pathway.

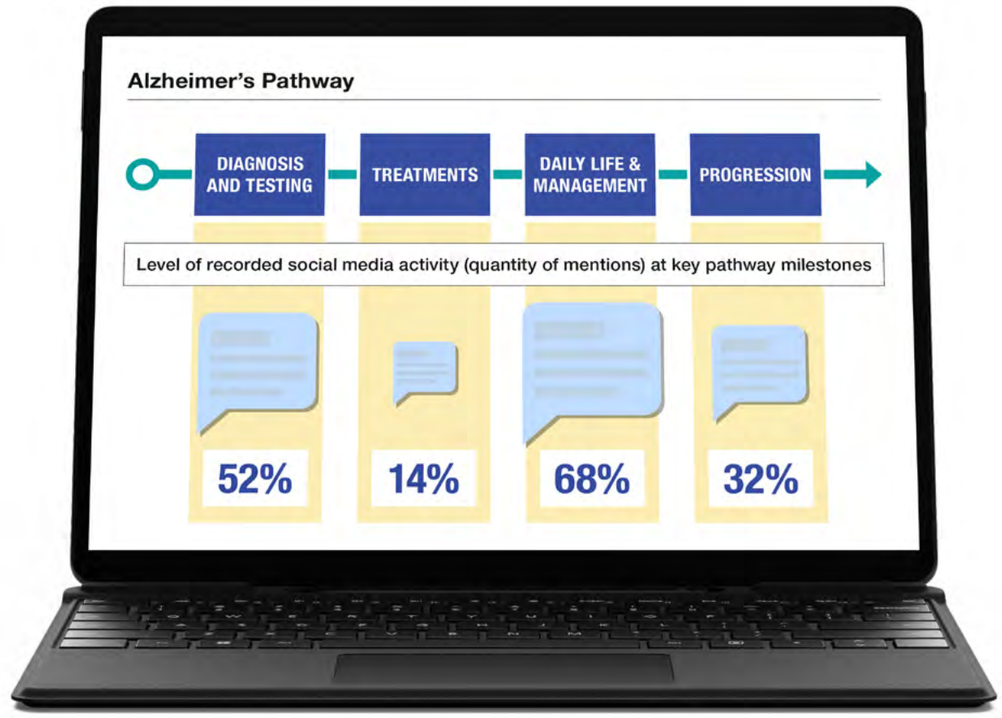
This, again, is a stage at which financial support and advice is needed. There was expressed worry of the patients having to use their savings for care, or care falling solely to loved ones in instances where money isn't readily available. Unlike the funding seen for healthcare in some areas, the same cannot be said for social care according to some contributors. A concern of inequality in terms of care and treatment provision was also inferred from some conversations on social media.



THE NEED FOR KNOWLEDGE

These four stages we've outlined have characteristics that are by no means exclusive to a particular stage. For example, documentation of patient confusion and distress at attending physician appointments is referenced throughout the entire journey and something caregivers increasingly shoulder the burden of. Knowledge seeking and the need for advice and support is not exclusive to one stage, but our research did show a varying extent of knowledge-seeking depending on a particular pathway point [FIG. 1].

FIG 1: Level of recorded social media activity at key Alzheimer's pathway milestones



Source: Synthesio (An Ipsos Company) – see *About the Research*

This is something the pharmaceutical industry can also be mindful of, and sympathetic to, recognising where and when any additional support they could provide as an industry would be best placed.

IN SUMMARY

Outside of the physical manifestations of this condition, the findings we discuss in this article highlight the many emotional and mental, as well as practical and financial, challenges faced by all those involved in the very complex Alzheimer's journey. This data emphasises a clear need for effective education and awareness among all stakeholders of the signs of Alzheimer's, the tendency for denial and hiding symptoms, as well as where to seek help. Given the manifestation of the disease, communication with HCPs and with the Alzheimer's community appears to be primarily driven by the caregiver, and to some extent they are the ones who suffer the most. Our analysis uncovered the heavy reliance on online support groups and the feeling that HCPs can be ill-equipped to deal with the psychological aspects of living with Alzheimer's that caregivers encounter. Therefore, there is a need for additional professional emotional support to provide caregivers more effective tools to deal with these challenges. Fundamentally, there is also a need to address the speed to diagnosis, which is critical in order for patients to access timely treatment.

Whilst there are areas in which the pharmaceutical industry may be unable to provide direct support, acknowledgement of the need for empathy at different stages of this journey will never be a wasted task. Companies can consider much wider messaging with a clear focus on the caregiver. This is important in terms of type of language and imagery that can be used and how this relates to treatment adherence and diagnosis rates. In our opinion, an increased number of available treatments and help facilitating early and appropriate access to them will always be welcomed and necessary.

A full report detailing results from this study is available. This report contains additional insight around the online sources caregivers are using to search for information, key topics discussed, and key questions asked, as well as further details for each of the patient journey stages. Please contact Ramya.Logendra@ipsos.com or Simone.Gabriele@ipsos.com for further details.

About the Research

Synthesio (an Ipsos Company)

Data were collected in the Synthesio platform from social media networks and online forums in USA, France, Germany, Italy, Spain, UK, Ireland, Japan and Canada between July 2021 and June 2022. The query was a combination of keywords centred around Alzheimer's disease and treatment options, alongside personal pronouns, translated for each of the required markets. Posts were analysed qualitatively first and foremost, with particular attention paid to those from patient / caregiver forums.

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