ARTICLE

Hope: a tool for working with families affected by dementia during the COVID-19 pandemic

Amy Pepper, Zena Aldridge & Karen Harrison Dening

SUMMARY

The COVID-19 pandemic significantly increased the challenges faced by families affected by dementia, leading to an immediate increase in both the number of calls received by Dementia UK's Admiral Nurse Dementia Helpline and the levels of distress and complexity of the calls. Consequently, Admiral nurses experienced feelings of helplessness, echoed in the experiences of other health professionals. One of the approaches that enabled Admiral nurses to cope during this time was 'hope', and this article explores the use of hope-based approaches as tools for working therapeutically with families during the pandemic. Although written from the perspective of Admiral nurses, the approaches described are transferable to others working across health and social care. The article provides an overview of one of the main models of hope in the healthcare literature, Snyder's hope model, and explores the literature on hope more widely. Fictitious case vignettes, drawn from clinical practice during the pandemic, are used to illustrate how hope-based approaches can be applied to practice.

LEARNING OBJECTIVES

After reading this article you will be able to:

- understand the theory of hope in relation to working with families affected by dementia
- understand and explore the impact of the COVID-19 pandemic on feelings and hope and hopelessness for families affected by dementia
- weigh up the evidence for hope-based approaches and understand when they may be useful in clinical practice when working with families affected by dementia.

KEYWORDS

Hope; dementia; COVID-19; family carers; Admiral nurses.

Amy Pepper is an Admiral nurse research assistant with the Research and Publications Team of Dementia UK, London, UK. Since qualifying as a mental health nurse in 2008 she has worked in various settings specialising in supporting families living with dementia. In 2014 she developed and led the Admiral Nursing Service in the London borough of Sutton, carrying out an evaluation of the role that led to an increase in funding and expansion of the team. **Zena Aldridge** is an Admiral nurse research fellow with Dementia UK, London, UK, a dementia nurse consultant with Norfolk and Waveney Clinical Commissioning Group, Norwich, UK, Regional Advisor (Dementia) for NHS Improvement and NHS England, London, UK, and a PhD student at de Montfort University, Leicester, UK. She has worked in health and social care for nearly 30 years, qualifying as a registered mental health nurse in 2003 and completing an MA in mental health in 2012. She became an Admiral nurse in 2013 and joined Dementia UK in 2016 as a service evaluator and senior consultant Admiral nurse before taking up her current post. **Karen Harrison Dening** is Head of Research and Publications for Admiral Nursing and Dementia UK, London, UK and Professor of Dementia Nursing at de Montfort University, Leicester, UK. She has over 45 years' experience in nursing, mostly in dementia care. For the past 15 years, she has worked with Dementia UK, initially as a consultant Admiral nurse, then the Director of Admiral Nursing before taking up her current post. She gained a PhD at University College London, London, UK focusing on advance care planning and end-of-life care in dementia. She has several honorary academic positions, one being an associate professor at the University of Nottingham, Nottingham, UK. **Correspondence** Amy Pepper. Email: amy.pepper@dementiauk.org

First received 15 Sep 2022
Final revision 22 Jun 2023
Accepted 23 Jun 2023

It is estimated that there are more than 900 000 people in the UK living with dementia (Wittenberg 2019). Dementia is an umbrella term used to describe a group of symptoms that are characterised by memory loss, behavioural changes, and loss of cognitive and social functioning caused by progressive neurological disorders. There are over 200 subtypes of dementia usually caused by neurodegenerative conditions, with the most common types being Alzheimer's disease, vascular dementia, Lewy body disease, mixed dementia (most often a combination of Alzheimer's disease and vascular dementia) and frontotemporal dementia (Sandilyan 2019). Lewis et al (2014) estimated that there are more than 700 000 unpaid carers in the UK supporting people with dementia and suggested that if the ratio of unpaid carers to people with dementia was to remain the same this number would need to increase to 1.7 million people by 2050.

Admiral nursing

Dementia UK is a charity that provides specialist support to families affected by dementia using the model of Admiral nursing. Admiral nurses are specialist nurses who have expert knowledge and skills in dementia care. They employ a range of evidence-based interventions to support families affected by dementia, both in terms of developing practical approaches for living with the symptoms of dementia and offering emotional support to help build resilience and coping strategies. The support provided by Admiral nurses can be offered peri-diagnostically (during the diagnostic process) and post-diagnostically, across the life course of the condition, through to end of life and after bereavement (Aldridge 2019). Admiral nurses work across a range of settings, including the community, acute hospitals, hospices, primary care, care homes and the Admiral Nurse Dementia Helpline. Although the composition, funding and remit of Admiral nurse services vary, their core principles and values remain the same (Aldridge 2019).

Telehealth

Blandford et al (2020) define telehealth as the provision and management of healthcare in which individuals (often working with family members) manage aspects of their care with remote support from

healthcare professionals. Prior to the COVID-19 pandemic, telephone helplines were becoming an increasingly common and integral component of healthcare delivery, often targeted to a specific condition or disease (Drayton 2020). Seen to be cost-effective and to offer a reach beyond traditional geographical boundaries, telehealth approaches are part of the wider response to support self-management as an increasing number of people live longer with chronic conditions (Amalberti 2019). The onset of the pandemic saw an unprecedented increase in the deployment of telehealth as many countries were forced into lockdown and, as a consequence of social distancing measures, there was a need to adapt models of care, leading to a rapid increase in telephone and video consultations (Blandford 2020).

The Admiral Nurse Dementia Helpline

The Admiral Nurse Dementia Helpline is one of four registered dementia helplines operating in the UK but is the only clinical dementia helpline staffed by specialist dementia nurses and offering a range of nursing interventions. It offers support via phone or email and operates 7 days a week and 5 evenings a week (Drayton 2020). The helpline is available for all, inclusive of: people concerned that they or someone close to them are experiencing symptoms that may be indicative of dementia; people with a diagnosis of dementia; families, friends and carers of people with dementia; and professionals who are caring for someone with dementia (Drayton 2020).

Impact of COVID-19 on people with dementia and their family carers

Living with dementia and caring for someone with dementia can be challenging at any time, but COVID-19 increased these challenges owing to the reduction in essential support services as restrictions were imposed (Cousins 2022; Suarez-Gonzalez 2021). It has been identified that people with dementia and their families were disproportionately negatively affected by the pandemic (Greenberg 2020). Memory assessment services paused operations, day centres shut down, support groups and activities closed or went virtual (Cousins 2022). Restrictions meant there was limited contact with anyone outside of the household, leading to increased social isolation, and for people living in care homes the enforced separation from family due to measures to reduce infection and the death rate went on for far longer (Suarez-Gonzalez 2021).

A rapid review by Suarez-Gonzalez et al (2021) found that people with dementia had experienced decline in cognition, a worsening of symptoms such as depression, apathy and anxiety and reduced functioning during the first year of the pandemic. Furthermore, there had been an increase in the prescribing of antipsychotic and benzodiazepine medication to manage behavioural and psychological symptoms. All of these issues are associated with increased caregiver burden and lower quality of life for people with dementia (Suarez-Gonzalez 2021).

Consequently, there was an immediate increase in not only the number of calls received by the Admiral Nurse Dementia Helpline at the onset of the pandemic, but also in the levels of reported distress and the complexity of the calls. The content of calls also changed significantly and there was a need to quickly adapt practice to respond effectively to callers. Admiral nurses on the helpline found they were suddenly unable to offer their usual advice on real-world support and coping strategies owing to the imposed restrictions and the sudden lack of access to resources. This led to them to experience feelings of helplessness, which have been echoed in the experiences of health workers across the board (Shaw 2020). One of the approaches that enabled Admiral nurses to cope during this time was ‘hope’.

Defining hope

In dictionary definitions, hope is described as a feeling of expectation, or a desire for a particular thing to happen, or grounds for believing that something good may happen. It can also be used as a verb: to hope is to want something to happen or to be the case. Hopelessness, on the other hand, can be defined as a feeling or state of despair, or a lack of hope. However, the literature on hope and health has found the concept hard to define (Cutcliffe 2002; Duggleby 2012). Hope is a very personal construct, meaning different things for different people. Cutcliffe & Herth (2002) examined the spiritual, philosophical and healthcare context of hope, and found that the literature lacked a definition that encompassed all that hope entails within these differing perspectives. In part this is due to the dynamic nature of hope, in that it may mean something different to a person recovering from disease, as opposed to someone living with a terminal or progressive illness. There is also variation in the methodological processes used to evaluate hope that make a clear conceptualisation difficult. Duggleby et al (2012), in a meta-synthesis of qualitative studies into hope relating specifically to older people with chronic illness, found that hope was a process of reappraising what was important to them, as well as what was realistic, giving a definition of hope in this context being ‘desirable (wanted) possibilities’.

Given the difficulties in clearly defining hope in the healthcare context from which to begin

exploring its use as a tool for nurses, this article will provide an overview of one of the main models of hope in the healthcare literature: Snyder's (2000) hope model.

Snyder's theory of hope

The American psychologist Richard Snyder wrote extensively on the subject of positive psychology, with much of his work focusing on the concept of hope. He developed a theory of hope, which he defined as 'a cognitive set that is based on a reciprocally derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals)' (Snyder 2000: pp. 8–9). He refers to the trilogy of goals, pathways and agency, which are central to his model (Box 1).

Snyder (2000) argues that hope does not disappear in challenging circumstances but can remain with those with a hopeful mindset who seem able to maintain optimism even in the most challenging situations. The theory is interesting from a clinical practice perspective as it characterises hope as a state of doing, rather than a state of being, therefore providing the potential to develop strategies and interventions to increase hope.

Looking at this theory through the lens of the pandemic, it is easy to see why families living with dementia might have struggled to maintain a hopeful mindset. The ability to visualise goals is challenged by the fact that we were all operating in uncharted territory during the pandemic, living with uncertainty and with no clear idea of what the future might look like in terms of restrictions and service availability. People who may have previously been able to generate multiple pathways towards a goal were challenged at every turn owing to ever-changing COVID-19-related policy alongside rising rates of death and infection, making it more difficult to maintain a hopeful mindset as goals became unobtainable. When the ability to act independently and of our own free will is taken away, as was the case under government restrictions, a person's ability to maintain agency thinking (Box 1) and determination is harmed.

When hope is challenged in the ways described above, the outcome can be feelings of hopelessness. Beck et al (1990) developed a model of hopelessness, defining it as negative expectations about ourselves and our future, characterised by being unable to find a solution or way out of our problems. The Beck Hopelessness Scale is widely used and has been shown to be a good predictor of suicidal ideation and suicidality (Beck 1990). Carers of people with dementia have a higher risk of suicide than the general population (O'Dwyer 2016) and they have been disproportionately affected by the pandemic (Suarez-Gonzalez 2021). However, it is still too early to draw firm conclusions about how this might translate into increased suicide risk as a result of restrictions imposed (John 2020). Considering hope and hopelessness as being on the same continuum, if we were to define hope by reversing Beck's definition of hopelessness (i.e. hope is having positive expectations about ourselves, characterised by being able to find solutions and ways out of our problems) then we can see how it maps directly onto the elements of Snyder's hope model (goals, pathways and agency thinking).

BOX 1 Central tenets of Snyder's hope model

Goals thinking – this refers to the ability to clearly visualise valuable and attainable goals

Pathways thinking – this refers to the ability to generate methods and plans to achieve goals: a person with high pathways thinking will be able to generate more than one pathway to reach a goal

Agency thinking – this is the motivational component of Snyder's theory and refers to the sense of determination, even when faced with obstacles.

(Snyder, 2000)

Why hope?

Before exploring practical hope-based approaches that might be useful in working with families living with dementia, it is helpful to consider the evidence base for using hope in practice more generally. Hope has a long history as a psychotherapeutic approach, and hope that things can change may be an important factor in the success of any therapeutic intervention (Lopez 2004).

Hopelessness has been associated with poorer health outcomes in older carers (Schulz 1999; O'Dwyer 2016). Hopelessness and depression have been associated with increased cardiac mortality and allostatic load (cumulative burden of chronic stress and life events) in the general population (Anda 1993; Gan 2014; Mitchell 2020) and can predict mortality in older adults (Furlanetto 2000; Stern 2001).

Schnoll et al (1998) showed that people with cancer had higher levels of hopelessness than the general population, but levels of hopelessness were not linked to the stage of disease, findings echoed in subsequent studies (Chen 2003; Chu-Hui-Lin Chi 2007). What seemed to be a more significant predictor of hopelessness in this cohort was negative coping strategies (Schnoll 1998), which suggests the

BJPsych Advances (2024), vol. 30, 156–163 doi: 10.1192/bja.2023.38

possibility that we can increase feelings of hope, even in what might be considered a hopeless situation.

This is mirrored in some of the literature on terminal illness (Sullivan 2003; Woelk 2008; Brashear 2019), which talks about hope being possible even when the hope of survival is gone. For people approaching the end of life, hopelessness is not an absence of hope, but rather an attachment to a form of hope that is lost (Sullivan 2003). This has many parallels with the situation of families living with dementia throughout the pandemic: the world was not the same as it was, and they did not know if or when things would return to 'normal'. As is the case for professionals working with people at the end of life, the challenge for professionals supporting families living with dementia is to enable them to diversify or redirect their perception of hope.

Practice examples

We now consider hope through the lens of three case vignettes, which are based on calls received by the Admiral Nurse Dementia Helpline during the pandemic. Each fictitious vignette will provide the basis for exploring the literature on hope-based approaches and looking at how these can be used in practice to support families living with dementia.

Case vignette 1: Nancy

> Nancy called the helpline in a heightened state of distress, opening the call by saying she didn't know where to start. She was encouraged to tell her story. Nancy cares for her mother, who has dementia, and she has no siblings. She has been told to shield and so since the start of the pandemic has been managing her mother's care remotely. During this time, she has supported her mother through a hospital admission and initiating a new home care package over the phone and by utilising a network of support from friends, family and professionals. Her mother can't understand or remember the 'stay at home' advice and keeps leaving to go to the shops. Nancy feels overwhelmed by the task of keeping her mother safe at home.

Ghazavi et al (2015) describe the use of structured hope therapy for people with diabetes and highlight some of the specific approaches shown to be helpful in increasing levels of hope. Central to their idea of hope therapy in this context is allowing the person to tell their story. Using counselling and active listening skills will be familiar to those working with families affected by dementia (Freshwater 2003); such a narrative approach allows us not only to build a trusting relationship, but also to highlight exceptions. These exceptions, or 'sparkles of hope' (Ghazavi 2015), are times when the person did not have the current problem, or when they overcame similar problems or when they were able to cope well with other negative events.

In the case of Nancy, this approach was used to encourage her to tell the story of how she has supported her mother during the pandemic. As part of this storytelling, Nancy was invited to explore the various ways she had overcome the challenges earlier in the pandemic, for example, supporting her mother remotely during a hospital admission. Therapeutic pauses (the use of silence to encourage reflection) were utilised to enable Nancy to recognise her strengths and resilience, so that she could acknowledge them herself, which also helped her focus in on the positive statements she was making about herself and her situation, allowing her to reframe things. If Nancy was struggling to gain this insight on her own, then the Admiral nurse might use reflection of her story and invite her to identify and explore the many challenges she has overcome. In doing so Nancy's story becomes a therapeutic tool that we can use to highlight her inherent resilience, focusing on her strengths and validating her past successes in caring for her mother and keeping her safe. Although simply talking through strategies to remind her mother to stay indoors may be helpful, what the hope-based approach adds is to highlight Nancy's skills and strengths, allowing her to move forward with any advice and confidently put it into practice.

Case vignette 2: Bob

> Bob calls the helpline expressing feelings of hopelessness. His wife, whom he adores, moved to a care home 6 months before the outbreak of the pandemic. He had visited her daily but has now not been able to see her for some months. Window visits have failed as she does not understand and becomes upset at not being able to touch Bob.

A study by Moore et al (2014) examining the impact of a nurse-led hope-based group approach for nursing home residents offers some practical approaches that could be applied to working with families living with dementia during the pandemic. The approach highlights how nurses, regardless of the clinical setting, have an opportunity to instil hope in the people they work with.

The model used for the Moore et al (2014) group approach was based on the book *Finding Hope: Ways to See Life in a Brighter Light* (Jevne 1999). The book provided a plan and focus for each of the group sessions. One of the themes that arose from the evaluation of this hope-based group approach was the concept of 'thinking about hope more intentionally' (Jevne 1999: p. 6), with participants reporting benefits following time spent talking and thinking explicitly about hope. It encouraged them to start seeing hope in their day-to-day lives and the social dimension of the group approach saw them supporting each other to find hope in difficult circumstances.

The questions used in the sessions provided useful practical approaches for starting conversations about hope in practice and can be found in Box 2. These questions can be used to explore ways of eliciting hope in families living with dementia.

Applying this approach to Bob's expressed hopelessness enabled an opportunity to explore what hope meant to him. The questions were used to help Bob to explore things that had helped him to have hope in the past. This exploration can be used to empower Bob to move towards finding new ways to find hope in the here and now. Questions about control can be used to help him to explore the things he can change and help him move towards an acceptance of the things that he cannot. For example, Bob is unable to control the restrictions on visiting his wife, or his wife's reaction to the window visits. However, using the question about what he can control helped him to start to explore other ways of keeping in contact with his wife. During the call to the helpline Bob was able to formulate a plan to start writing letters to his wife and asking the care home staff to read them to her and help her to write back to him. Although it was discussed that video calls may cause similar distress to the window visits, Bob was able to consider the idea of taking photographs to send to the home and asking the care home staff to do the same in return. Imagining another perspective took Bob back to the early days of courting his wife when he would write her love letters.

Thinking about a thing he could do this week to make a small difference opened up discussion about self-care measures he could use when he was finding the separation from his wife hard to bear. Following the call Bob expressed a renewed sense of hope that his connection with his wife could be maintained and that he could better cope with the inevitable feelings of sadness and loss caused by the visiting restrictions.

BOX 2 Questions offering practical approaches to starting conversations about hope

- What is hope?
- How do you define hope for yourself?
- What are the signs of hope you notice in everyday life?
- What voices of hope have you heard?
- What are your hope stories?
- Where have you found hope that surprised you?
- Where have you noticed hope that you wouldn't have expected?
- In what ways have you ever given or lent hope to another person?
- Have there been times that you felt someone gave you hope?
- What are the things that are under your control?
- What are the things that are not under your control?
- What are some of the ways this situation might turn out better than expected?
- How might you imagine another perspective?
- What can you do this week that will make a small difference?
- How will you choose to make hope more visible?

(Moore et al, 2014)

Case vignette 3: Brenda

Brenda calls the helpline asking where to get support and respite, as she has been caring for her husband single-handed since the start of the pandemic. They have not left their house and have stopped all family visits, which had been giving Brenda a much needed break. Brenda is exhausted and as a result the relationship between her and her husband is strained. During the call it becomes apparent that Brenda has already tried many of the avenues being suggested. She says that she can't see a way for things to improve and feels life is not worth living.

Kondrat & Teater (2010) explored the potential of using accident and emergency department encounters with suicidal patients to increase their levels of hope, utilising principles from solution-focused therapy (SFT). SFT is a goal-oriented therapeutic approach based on the construction of solutions rather than focusing on problems (O'Connell 2005). The approach is short term in nature, making it useful for nurses working in various settings and especially in a one-off encounter such as a helpline, and can be helpful when working with people experiencing suicidal thoughts, as well as those lacking in hope more generally (Kondrat 2010). Kondrat & Teater posit that using principles from SFT may provide a therapeutic intervention to increase hope, concurring with a number of studies that have demonstrated that SFT approaches can be effective in increasing hope (Michael 2000; Greene 2006).

There are three assumptions of SFT that appear relevant when working with hope:

(a) people are resourceful and full of strengths, and these strengths often go unnoticed by the person
(b) exceptions to problems lead to construction of solutions
(c) change is constant and recognition of this can help support changes in thinking about problems.

There are clear links between SFT and Snyder's theory of hope (Kondrat 2010); SFT helps people develop goals and recognise their strengths and

BJPsych Advances (2024), vol. 30, 156–163 doi: 10.1192/bja.2023.38

exceptions to the problem, which promotes the pathways and agency thinking Snyder (2000) talks about as being essential to having hope.

Questioning techniques

Goal questions

From a practice perspective, there are techniques to questioning in SFT that may prove helpful in developing and exploring hope in short therapeutic encounters. The first of these is the use of goal questions, the purpose of which is to help the person to construct well-defined goals. Often in nursing practice people come to us with a specific goal; however, someone like Brenda, who is feeling overwhelmed by hopelessness, may be unsure about their goals and what they need to change in order to meet them. In such instances the 'miracle question' can be a helpful tool. There are variations on the miracle question, depending on the setting it is being used in, but in essence the question is 'Suppose there was a miracle overnight and while you were sleeping the problem you have was solved. How would you know this had happened? What would be different?' (O'Connell 2005).

If Brenda struggles to answer this, further exploratory questions can be asked, such as 'What is the first thing you would notice?' and 'What would someone close to you notice about you now the problem was solved?' This questioning technique can help Brenda begin the process of problem-solving and take an active part in the process of identifying her own goals.

Exception questions

Another questioning technique is the use of exception questions, which are echoed in the above discussion of the narrative hope-based approach. These questions are focused on exploring times at which the person did not have the problem they are currently experiencing, or when they dealt with previous problems well. Looking at the example of Brenda's situation, we might ask 'Can you think of a time recently when you felt rested, or when the relationship between you and your husband was good?'. Brenda may struggle to identify an exception, in which case the next step would be to ask a strengths-based question, for example 'How have you been able to cope with things being so difficult since the start of the pandemic?'

The purpose of these exception questions is to help Brenda start to see herself as capable and strong, promoting her sense of 'pathways thinking' (her ability to problem solve despite obstacles) and agency (her ability to act independently to improve her situation) (Snyder 2000). Through this line of questioning, we can start to highlight the resilience she has shown during her extended period of isolation and begin to work towards her rediscovering a sense of hope.

Scaling questions

A further type of questioning is the use of scaling questions. These can be used to assess level of risk and may be utilised with Brenda to ascertain how likely she is to harm herself, given the thoughts she has expressed about life not being worth living (Kondrat 2010). We might ask her to rate on a scale of 1–10 how confident she feels about getting through the next day or week without harming herself. Scaling questions can be used creatively, for example asking Brenda to rate her ability to cope, her motivations to change and her confidence in being able to effect changes in her life. They are a useful tool in helping Brenda take an active part in the assessment of both her level of risk and her own needs. These questions could offer a tool for nurses who are working with families living with dementia, particularly in assessing the risk of someone presenting with high expressed hopelessness or with suicidal ideation, and enable the person to work with the nurse to assess the need for urgent intervention.

Relationship questions

The final questioning technique is that of relationship questions. These are helpful when the person is struggling to see their strengths or identify exceptions, and can be used to put a different slant on the other question types. So, for example, if Brenda was struggling to answer any of the questions above we might ask her 'What would your family and friends say about how you have coped with things being so difficult?' or 'How would your family rate your ability to cope with things right now?'.

An evidence-based approach

The use of these SFT questioning approaches provides an evidence-based approach that can support the formation of goals, agency and pathways thinking, which fits with Snyder's (2000) model of hopeful thinking. The brevity of this approach makes it useful for nurses working in a variety of settings, and especially when there may be short window of time in which to help someone feel more hopeful, as is the case within the Admiral Nurse Dementia Helpline.

Implications for practice – COVID-19 and beyond

The COVID-19 pandemic threw both professionals and families living with dementia into an

MCQ answers
1 c 2 a 3 c 4 c 5 b

unprecedented situation. Families affected by dementia had to learn to cope with a stripped back NHS and social care system, increased isolation and lack of social and family support. As professionals we had to quickly adapt our practice and the interventions we offer to support families during difficult and challenging times. Added to that, many professionals were personally affected by COVID-19 and felt some of the same feelings of hopelessness felt by the families they were supporting.

This exploration of the literature on hope as an intervention has highlighted its connection to, and influence on, a range of health outcomes, and the necessity of hope in achieving good quality of life, even when faced with seemingly impossible situations, such as being separated from a loved one in a care home. It has demonstrated that a range of hope-based approaches can be successfully integrated into existing care practices and interventions, to support families living with dementia through what has, at times, felt like a hopeless situation.

As well as being of benefit to families living with dementia, the integration of hope as an intentional therapeutic approach was also of benefit to the professionals using these approaches. As Flaskas (2007) notes in a paper on hope and hopelessness in the context of family therapy, there can be a tendency for us as professionals to attune to the feelings of hopelessness within the families we work with, and holding hope when we ourselves might feel hopeless about their situation can be challenging. By using hope-based approaches the nurses on the helpline were able to stay open to the possibility of the situations families presented with, while still acknowledging the despair they felt in the moment. The use of hope in this way allowed the nurses to cope with the relentless emotional work of supporting so many families in what might be described as hopeless situations. In this way the interventions discussed in this article would be helpful for mental health professionals more broadly.

Although the COVID-19 pandemic may have forced our focus on to the concept of hope and ways to preserve it during a difficult period, there would appear to be an important place for hope as a tool when working with families living with dementia beyond that extrodinary situation.

Future research may be of benefit in exploring the ways in which hope is being used in nursing practice in the field of dementia care and the experience of hope-based interventions from the perspective of people with dementia and their families.

Author contributions

A.P. was the lead author, and Z.A. and K.H.D. made significant contributions to the drafting, writing and revision of this article.

Funding

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Declaration of interest

None.

References

Aldridge Z, Harrison Dening K (2019) Admiral Nursing in primary care: peri and post-diagnostic support for families affected by dementia within the UK primary care network model. *OBM Geriatrics*, **3**(4): 081.

Amalberti R, Vincent C, Nicklin W, et al (2019) Coping with more people with more illness. Part 1: the nature of the challenge and the implications for safety and quality. *International Journal of Quality Health Care*, **31**: 154–8.

Anda R, Williamson D, Jones D, et al (1993) Depressed affect, hopelessness, and the risk of ischemic heart disease in a cohort of U.S adults. *Epidemiology*, **4**: 285–94.

Beck AT, Brown G, Berchick RJ, et al (1990) Relationship between hopelessness and ultimate suicide: a replication with psychiatric outpatients. *American Journal of Psychiatry*, **147**: 190–5.

Blandford A, Wesson J, Amalberti R, et al (2020) Opportunities and challenges for telehealth within and beyond, a pandemic. *Lancet Global Health*, **8**(11): e1364–5.

Brashear N (2019) How is hope reimagined at the end of life? *Clinical Journal of Oncology Nursing*, **23**(4): 448.

Chen ML (2003) Pain and hope in patients with cancer: a role for cognition. *Cancer Nursing*, **26**: 61–7.

Chu-Hui-Lin Chi G (2007) The role of hope in patients with cancer. *Oncology Nursing Forum*, **34**: 415–24.

Cousins E, de Vries K, Harrison Dening K (2022) '*Four walls and a garden*': exploring the experiences of families affected by dementia during the COVID-19 pandemic. *Dementia*, **21**: 810–29.

Cutcliffe JR, Herth K (2002) The concept of hope in nursing 1: its origins, background and nature. *British Journal of Nursing*, **11**: 832–40.

Drayton S, Harrison Dening K (2020) Achieving positive outcomes in complex cases: the Admiral Nurse Dementia Helpline (innovative practice). *Dementia*, **19**: 1308–15.

Duggleby W, Hicks D, Nekolaichuk C, et al (2012) Hope, older adults, and chronic illness: a metasynthesis of qualitative research. *Journal of Advanced Nursing*, **68**: 1211–23.

Flaskas C (2007) Holding hope and hopelessness: therapeutic engagements with the balance of hope. *Journal of Family Therapy*, **29**: 186–202.

Freshwater D (2003) *Counselling Skills for Nurses, Midwives and Health Visitors*. Open University Press.

Furlanetto LM, von Ammon Cavanaugh S, Romildo Bueno J, et al (2000) Association between depressive symptoms and mortality in medical inpatients. *Psychosomatics*, **41**: 426–32.

Gan Y, Gong Y, Tong X, et al (2014) Depression and the risk of coronary heart disease: a meta-analysis of prospective cohort studies. *BMC Psychiatry*, **14**: 371.

Ghazavi Z, Khaledi-Sardashti F, Kajbaf MB, et al (2015) Effect of hope therapy on the hope of diabetic patients. *Iranian Journal of Nursing and Midwifery Research*, **20**: 75–80.

Greenberg NE, Wallick A, Brown LM (2020) Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with

dementia. *Psychological Trauma: Theory, Research, Practice, and Policy*, **12**(suppl 1): s220–1.

Greene GJ, Kondrat DC, Lee MY, et al (2006) A solution-focused approach to case management and recovery with consumers who have severe mental disability. *Families in Society*, **87**: 339–50.

Jevne RF, Miller J (1999) *Finding Hope: Ways to See Life in a Brighter Light*. Willowgreen Publishing.

John A, Okolie C, Eyles E, et al (2020) The impact of the COVID-19 pandemic on self-harm and suicidal behaviour: a living systematic review. *F1000Research*, **9**: 1097.

Kondrat DC, Teater B (2010) Solution-focused therapy in and emergency room setting: increasing hope in persons presenting with suicidal ideation. *Journal of Social Work*, **12**: 3–15.

Lewis F, Karlsberg Schaffer S, Sussex J, et al (2014) *The Trajectory of Dementia in the UK – Making a Difference*. Office of Health Economics.

Lopez SJ, Snyder CR, Magyar-Moe JL, et al (2004) Strategies for accentuating hope. In *Positive Psychology in Practice* (eds PA Linley, S Joseph): 388–404. John Wiley & Sons.

Michael ST, Taylor JD, Cheavens J (2000) Hope theory as applied to brief treatments: problem-solving and solution-focused therapies. In *Handbook of Hope: Theory, Measures, and Applications* (ed CR Snyder): 151–66. Academic Press.

Mitchell UA, Dellor ED, Sharif MZ, et al (2020) When is hope enough? Hopefulness, discrimination and racial/ethnic disparities in allostatic load. *Behavioral Medicine*, **46**: 189–201.

Moore S, Hall SE, Jackson J (2014) Exploring the experience of nursing home residents participation in a hope-focused group. *Nursing Research and Practice*, **2014**: 623082.

O'Connell B (2005) *Solution-Focused Therapy* (2nd edn). Sage Publications.

O'Dwyer ST, Moyle W, Zimmer-Gembeck M, et al (2016) Suicidal ideation in family carers of people with dementia. *Aging & Mental Health*, **20**: 222–30.

Sandilyan MB, Dening T (2019) What is dementia? In *Evidence Based Practice in Dementia for Nurses and Nursing Students* (ed K Harrison Dening): 12–26. Jessica Kingsley.

Schnoll RA, Harlow LL, Stolbach LL, et al (1998) A structural model of the relationships among stage of disease, age, coping and psychological adjustment in women with breast cancer. *Psychooncology*, **7**: 69–77.

Schulz R, Beach SR (1999) Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*, **282**: 2215–9.

Shaw SCK (2020) Hopelessness, helplessness and resilience: the importance of safeguarding our trainees' mental wellbeing during the COVID-19 pandemic. *Nurse Education Practice*, **44**: 102780.

Snyder CR (2000) *Handbook of Hope: Theory, Measures, and Applications*. Academic Press.

Stern SL, Dhanda R, Hazuda HP (2001) Hopelessness predicts mortality in older Mexican and European Americans. *Psychosomatic Medicine*, **63**: 344–51.

Suarez-Gonzalez A, Rajagopalan J, Livingston G, et al (2021) The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: a rapid systematic review of one year of evidence. *eClinicalMedicine*, **39**: 101047.

Sullivan MD (2003) Hope and hopelessness at the end of life. *American Journal of Geriatric Psychiatry*, **11**: 393–405.

Wittenberg R, Hu B, Barraza-Araiza L, et al (2019) *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom, 2019–2040 (CPEC Working Paper 5)*. London School of Economics and Political Science.

Woelk CJ (2008) Management of hope. *Canadian Family Physician*, **54**: 1243–5.

MCQs

Select the single best option for each question stem

1 According to Suarez-Gonzalez et al (2021), in which ways were people with dementia affected during the first year of the pandemic?
- a they were forced to move to nursing homes
- b they experienced increased levels of psychosis
- c they experienced decline in cognition and a worsening of symptoms such as depression, apathy and anxiety
- d prescribing of opioid pain relief increased
- e they found it easier to access services.

2 'Pathways thinking' as outlined in Snyder's model of hope may be best defined as:
- a the ability to generate methods and plans to achieve goals
- b the ability to follow a prescribed path
- c being able to think about the route out of one's problems
- d having a sense of determination
- e being able to visualise goals.

3 Which approach is central to Ghazavi et al's structured hope therapy approach?
- a a solution-focused approach
- b a cognitive–behavioural therapy approach
- c a narrative approach
- d a family therapy approach
- e a psychoanalytic approach.

4 An 'assumption' of the solution-focused therapy (SFT) approach is that:
- a there is always an easy solution to every problem
- b people often need to be told how to solve their problems
- c exceptions to problems lead to construction of solutions
- d people need to be more motivated to solve their problems
- e self-determination is key to problem-solving.

5 Which type of questioning technique in the SFT approach might be helpful in assessing levels suicide or self-harm risk?
- a relationship questions
- b scaling questions
- c goals questions
- d exception questions
- e the miracle question.