Hope and dementia

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Abstract

Dementia is a terminal and progressive condition which often brings with it a loss of hope, and feelings of hopelessness in those living with the condition and their family carers. Community nurses are in a unique position of being able to interact with people with dementia and their family carers in their own homes, or the care settings in which they reside, and in some case, will be the only professionals with regular contact with the family. Therefore, they have the opportunity to increase feelings of hope in those they work with. This article will discuss the concept of hope as it relates to dementia. It goes on to give an overview of Snyder's model of hope, which presents hope as a cognitive state, and therefore presents the opportunity for professionals to increase feelings of hope. An overview of the research evidence around hope-based interventions is then given, with the ideas applied to community nursing practice using a case study. This article aims to add some hope-based interventions to the toolkit of community nurses as they work with people and families affected by dementia.

Keywords: Hope • dementia • nursing • psychosocial interventions

The term dementia describes a group of symptoms including changes to behaviour, cognition and social functioning caused by progressive neurological disorders (Barber, 2020). The most common type of dementia is Alzheimer's disease, with other commonly seen subtypes including vascular dementia, dementia with Lewy Bodies and frontotemporal dementia (Sandilyan and Dening, 2019). While most common in those over the age of 65 years, dementia can also occur in younger people (termed young onset dementia) (Carter et al, 2022). It is estimated that there are currently 950 000 people with dementia in the UK and this is set to increase to 1.6 million by 2040 (Wittenberg et al, 2019). People living with dementia are often supported by a family carer. This can have a significant emotional, physical and financial impact on the carer (Farina at el, 2017). Dementia is a terminal condition, leading to progressive loss of ability and eventually, death. Despite this, there is a growing interest in the concept of hope as it relates to those with dementia and their family carers (Duggleby at al, 2013; Pepper et al, 2023).

Hope

Hope is a very personal construct, meaning different things for different people, and it is likely to change over the course of time. We are all able to think of things which give us hope when things get difficult in our lives; however, it is unlikely that those factors that personally create hope for us, will do the same for someone else. Within the wide range of human experience, hope is therefore a dynamic and multifaceted phenomenon. It has been written about from many different perspectives, including the spiritual, psychological, philosophical and sociological (Cutcliffe and Herth, 2002). Additionally, it has been explored in relation to nursing, in diverse fields such as terminal illness and long-term conditions (Cutcliffe and Herth, 2002). Given the very personal nature of hope, and the range of contexts in which it may be applied, one standard definition is elusive. A dictionary definition would describe hope as a feeling of expectation or 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 be the case. Where hope is lacking, hopelessness may be the outcome, and this is better defined in healthcare literature, with Beck (1990) writing extensively on his theory of hopelessness, resulting in the Hopelessness Scale, which has been shown to be a good indicator of suicidal intent.

Snyder's model of hope

Snyder's model of hope provides a structured framework for understanding the cognitive processes underlying hope, emphasising goal-directed thinking and the motivation to pursue those goals. Within his model, Snyder defines hope as:

> *'a positive cognitive state based on a sense of successful goal-directed determination and planning to meet these goals.' (Snyder, 2000; p8)*

Snyder's theory is of interest to nurses working with people with dementia as he characterises hope as a state of doing, rather than a state of being, therefore, allowing the possibility of finding ways to increase feelings of hope among those we work with. Snyder sees hope as a life-sustaining human strength which is comprised of three distinct, but related, concepts (*Figure 1*).

Goals thinking refers to the ability to clearly visualise valuable and attainable goals. *Pathways thinking* refers to a person's ability to generate methods and make plans to achieve those goals. A person with a high level of pathways thinking will be able to generate more than one pathway to reach a certain goal, being able to re-think a pathway should an obstacle emerge. Finally, *agency thinking* is the motivational component of Snyder's model and this refers to the sense of determination experienced by people, even when faced with obstacles or blocks when trying to reach goals.

Snyder's model allows for hope to remain, even in very challenging circumstances; for example, following a diagnosis of dementia. Those that are able to maintain, or develop, a hopeful mindset, are likely to retain a sense of optimism and quality of life. As nurses working alongside families affected

by dementia, an understanding of hope, and the ways in which we can support a hopeful mindset, is therefore of great importance.

If we consider Snyder's model from the perspective of a family affected by dementia, we can see how hopeful thinking can be challenged by those affected. The goals, once held, may need to shift radically; for example, plans for a retirement spent travelling or learning new skills and hobbies may need to be reconsidered following a diagnosis of dementia. The idea of a clearly defined goal may also be difficult to achieve with so many unknowns about how the dementia might progress and present for the individual person. Pathways to meet the new goals may also be challenged; for example, in terms of navigating a complex health and social care system that is not always well-defined for people with dementia. In addition, agency is likely to be taken away from a person with dementia as a result of their diagnosis, perhaps because the progression of their dementia means they are lacking capacity to make certain decisions for themselves; it may also be due to the stigma associated with dementia, and the assumption of others around them that they can no longer do things for themselves.

How can nurses increase hope in the people they work with?

In a busy community nursing role, it may feel outside of the scope of your practice to use hope-based interventions with people with dementia and their carers. However, research has shown that there are several ways hope-based approaches can be incorporated into day-to-day practice, to help the people you work with achieve a more hopeful mindset, and to support them with some of the challenges in delivering nursing interventions. The next part of this article will discuss the research evidence around hope-based approaches and consider them in the context of a case study to see how they could be applied by nurses working with people living with dementia, and their families.

One such example is the use of a structured hope therapy group for people living with diabetes (Ghazavi et al, 2015). Although not specific to people with dementia, the study highlighted approaches that were shown to be effective in increasing feelings of hope, that could be utilised by community nurses. Central to the positive outcomes achieved in this study were the opportunity for participants to tell their story, with a focus on times when they were able to overcome problems in the past. What was also found to be important was the time and support to be able to set achievable and realistic goals. While this study looked at the use of hope as a group intervention, it is possible to pick out the specific aspects that were found to be helpful and consider how it can be applied to community nursing practice in the context of dementia.

Another study using a group intervention (Moore et al, 2014) among nursing home residents also highlighted some practical approaches that can be used by nurses. The researcher used a book (Jevne and Miller, 1999) to provide structure to a nurse-led group intervention, which led to positive outcomes for all participants. Of interest to nurses was the theme arising from the data which related to the idea of intentionally thinking about hope. Participants who had the opportunity to talk explicitly about hope as part of the group, found that they began thinking about hope more intentionally outside of the group, finding hopeful aspects in their day-to-day lives. Although this research reports on a group intervention, the authors highlighted that their results indicate that nurses across all clinical settings have the opportunity to instil hope in their day-to-day interactions and care. A good starting point for this is to consider some of the questions used in the group hope intervention, which make useful prompts for starting conversations about hope in practice.

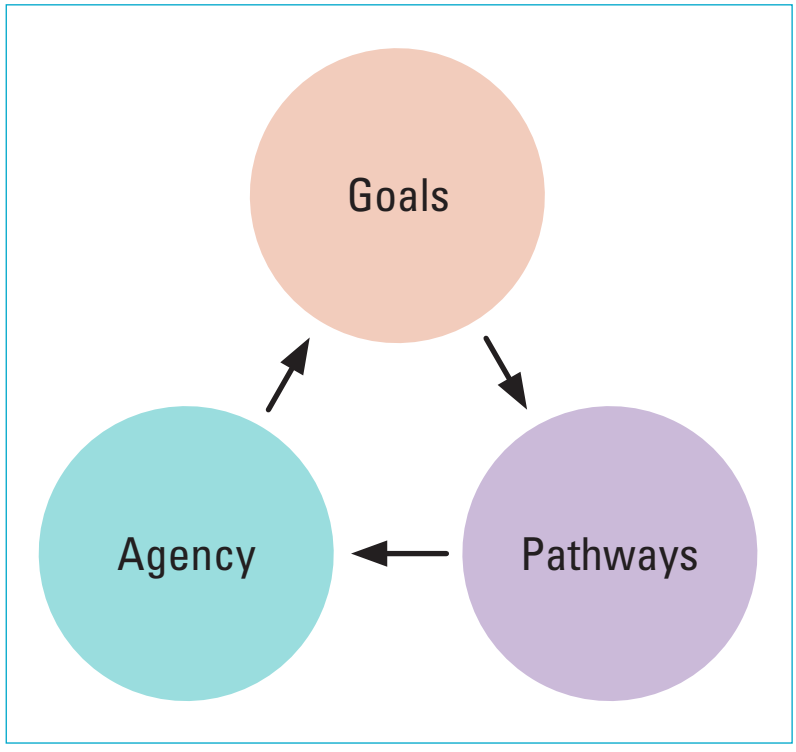

Figure 1. Snyder's model of hope

Hope-based approaches also have a strong overlap with those of solution focused therapy (SFT), and this is highlighted in the work of Kondrat and Teater (2010) who explored short clinical interactions (in the context of an A&E department) with suicidal patients, and how hope might be increased among these people. SFT has similarities with Snyder's model of hope, being goal-orientated in its approach, and as the title implies, focusing on creating solutions rather than the problems themselves (O'Connell, 2005). Therefore, promoting the pathways and agency thinking are central to Snyder's model. The short-term nature of SFT lends itself well to nurses working in a community setting who may only have a brief window of time with their patients. Kondrat and Teater (2010) go on to describe four questioning techniques that were helpful for increasing hope in these short encounters (*Box 1*).

Goal questions aim to support the person to construct a well-defined goal. In a therapeutic context, this is often framed as the 'miracle question' (*Box 2*), but in a nursing context, the goal may be less abstract. For example, working towards the healing of a wound, better controlled pain, or becoming more physically mobile after a fall. Exception questions help

Box 1. Questioning techniques for practice

- Goal questions: 'suppose there was a miracle overnight – how would you know?'
- Exception questions: 'when, over the last week, have you felt positive?'; 'How have you been able to cope with things being so difficult?'
- Scaling questions: 'on a scale of 1–10, how confident are you that you will make it through the day without harming yourself?'
- Relationship questions: 'what would someone else say about how you have been coping?'

people to look outside of their current problem, and consider times when things felt easier, or when they overcame a similar problem. They can be powerful tools in supporting people develop the pathways thinking needed for a hopeful mindset. Scaling questions can be used to gauge how confident or committed someone is to work towards a goal, to measure progress, or to assess risk in a collaborative way (for example, asking how confident a person feels about keeping themselves safe, on a scale of 1–10). Relationship questions can be used to look at any of the other questioning techniques from a slightly different perspective and can be helpful if the person is having difficulties answering them. For example, asking 'what would someone else say about how you have been coping with this level of pain for so long?'. All these questioning techniques provide strategies that can support the people we care for to engage in more hopeful thinking, by encouraging the formation of goals, agency and pathways thinking.

Another study explored the experience of hope in older adults by inviting them to take photographs that represented hope for them (Moore, 2012). Similar to some to the other research discussed above, the participants found therapeutic value in the simple task of being asked to think about hope more implicitly, with hopefulness in this context appearing to grow from the act of looking for hope in their everyday lives. Photography was used as a medium as it was hoped this would make it easier to think about a concept that can be quite abstract, and for that concept to be made visible through the participants' eyes. Interestingly, however, some participants chose not to create photographs, feeling that they could better express their ideas about hope through other means. Others chose to use old photographs that had meaning to them, to represent hope. The findings from this study conceptualised hope as being about belief and attitude (cognition), action (doing), and how one lives in the world (experience), which are broadly in line with the goals, pathways and agency components in Snyder's model. As a community nurse, you may not be setting a photography assignment for the people in your care; however, it is worth considering the value of the more creative approaches to instilling hope in people living with dementia and their carers that we care for. Photographs that may be in and around the home can provide invitations for reflection, prompt conversation and generate narratives. Reflecting on photographs or other treasured objects around the home can also be used to lead to questions about hope, and can support people to think about hope more intentionally.

Box 2. Hope questions for practice. Adapted from Moore et al (2014)

- 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 would not 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?

Putting hope into practice

Through a case-study approach (*Box 3*), we will now consider how some of the approaches from the research on hope-based interventions can be applied when working with people living with dementia, and their carers.

Anita is expressing a degree of hopelessness about her current situation, brought about by her loss of confidence following her fall, and fear that she may fall again. The community nurse has a unique opportunity to carry out some brief hope-based interventions in order to support Anita to move forward positively. Starting with the narrative approach, the nurse might encourage Anita to talk about times when she has struggled with loss of confidence in the past, or times when the losses associated with her dementia have felt difficult to navigate. This narrative approach could be enhanced further by thinking about some of the creative methods discussed above (Moore, 2012) and the nurse might make references to photographs or objects in the home to support conversations about what gives Anita hope in her life. This could then lead to the use of exception questions, when the nurse asks Anita to talk about times she has felt more positive over the last week or so. It may be that Antia's sense of hopelessness about her current situation is so pervasive that she cannot think of a time recently when she has felt more positive. In this case, the exception questions could be given a slight chance of focus, asking Anita to think of times when she coped well with the difficulties associated with her dementia or her physical health. Considering these exceptions will support Anita in feeling she has agency (or control) over what happens to her, and can help her think about pathways out of her current situation. Another important aspect of helping Anita achieve a more hopeful mindset would then be to support her in setting a goal to work towards. This could be very small at first, such a going for a short walk outside, or even within the house. These are all very brief interventions, that can be carried out alongside the nursing task of changing Anita's dressing, but which can help promote the pathways thinking, and the agency needed to allow Anita to start to work towards meeting a new goal and increasing her feelings of hope.

Box 3. Case study – Anita and Dev

Anita was diagnosed with Alzheimer's disease around 4 years ago. She lives at home with her husband Dev who is her main carer. Recently, Anita had a fall at home and sustained an injury to her left calf. You have been visiting her for a few weeks to change the dressing on her leg. During your visits you notice that Anita is becoming increasingly despondent about her situation. The wound is taking longer than expected to heal, and her confidence in mobilising has been dented by the fall. She tells you that she has not stopped going out of the house and expresses that this is another aspect of her life that has now been taken away from her due to her dementia.

A few years down the line, you are again visiting Anita and Dev at home, this time because Anita is now approaching the end of life and needs palliative care. She has stopped eating and drinking and is likely to be in her last few days of life. While visiting to set up a syringe driver to manage her pain, you find Dev very upset and tearful. He tells you that he can not imagine a life without Anita and discloses that he has been thinking about ending his life when she dies.

While being confident in delivering these brief hope-based interventions with people with dementia can make up an important part of the community nurse's 'toolkit', it is also important to recognise when someone might need more support due to feelings of hopelessness. If Anita's expressions of hopelessness persisted, and there were indications she may be experiencing depression, or be at any risk of harming herself, then onward referrals to appropriate health professionals should be made (for example the general practitioner or the community mental health team).

It is clear that Dev is experiencing profound feelings of hopelessness related to the imminent loss of Anita. Given his clear disclosure that he has been experiencing suicidal ideation, it will be important to make sure this risk is appropriately managed by making onward referrals to support him. But how might the community nurse be able to support Dev using hope-based approaches during the interaction with him? Here, it might be useful to think about the questions posed in the hope-based group discussed above (*Box 2*). Posing some of these questions would allow Dev the opportunity to think about hope more intentionally; this might be as simple as asking him what hope means for him, or what things give him hope. It may also be helpful to ask questions around what he feels he has and does not have control of. This might help him to formulate some goals, although the nature of these goals may be quite different to those used with Anita. It can be difficult to find hope within an end-of-life situation; however, much of the writing on hope and terminal illness shows that having hope is possible, even in what might be considered hopeless situations (Sullivan, 2003). What can be helpful as a focus for professionals in these situations is supporting people to diversify their hope. With this in mind, the goals for Dev currently might not be around helping Anita to survive, or extend her life, but perhaps being able to support her to stay at home, or for her pain to be managed well at the end of her life. There might also be internal goals for Dev, perhaps to reach out to a friend or family member for support for himself, or to take the step of seeing his own general practitioner and asking for help.

The scaling questions described above (Kondrat and Teater, 2010) might also be helpful here, as they can help gauge the level of risk presented by Dev's suicidal ideation. Asking scaling questions involves Dev directly in this assessment of risk, and subsequently, planning to manage it, thus, increasing his feelings of agency and supporting him in developing his pathways thinking (for example, what he will do to keep himself safe). As with the first part of the case study, it will be important that any immediate risks to Dev's safety are addressed in line with local safeguarding procedures and onward referrals are made to address his mental health.

Conclusion

This article has discussed one of the main theories of hope and examined the research evidence around ways hope can be incorporated into everyday nursing practice. As nurses, we are in a unique position to be able to increase feelings of hope in the people we work with, and this article has given examples of how very brief interventions can be used alongside day-to-day nursing tasks to support people to feel more hopeful. **BJCN**

Declaration of interest: *None*

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Key points

- Dementia is a progressive, terminal illness and as such, people with a diagnosis of dementia and their families are at greater risk of experiencing feelings of hopelessness, which can have a negative impact on both mental and physical health, and wellbeing
- Snyder's theoretical model of hope suggests a process by which feelings of hope can be increased, and a number of therapeutic approaches based on hope have been shown to be effective for people with dementia and their families
- An understanding of the theory of hopeful thinking and the therapeutic approaches that can increase feelings of hope can support community nurses to weave hope-based approaches into their day-to-day encounters with people with dementia and their families.

CPD reflective questions

- Think about things in life that make you hopeful – how might these be challenged if you, or someone close to you, was to receive a diagnosis of dementia?
- Thinking about Snyder's model of hope; what do you think might be some of the challenges to achieving the goals, pathways and agency thinking needed for a hopeful mindset after receiving a diagnosis of dementia?
- Looking at the questioning techniques in *Box 1*, can you think of a case from your recent clinical practice where these might have been useful? What might the outcomes have been of using this approach?

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