Role of the community nurse in supporting person-centred end of life care

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Abstract

Supporting end of life care is an important part of community nursing. Pressures on community nurses are ever-increasing as they strive to meet the needs of patients who are at the end of life. Interactions between patients approaching the end of life and healthcare practitioners can be challenging, since talking about death and dying, and planning for the future, is often emotive and may test the skills and personal values of the healthcare practitioner. This article details some of the challenges that community nurses may experience, and explains how to address these to support effective, person-centred end of life practice. It also encourages nurses to reflect on the complex nature of end of life care and the effects that providing such care may have on their well-being.

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Keywords

Aims and intended learning outcomes

The aim of this article is to enhance community nurses' understanding of the needs of people who wish to die at home. To facilitate a home death, nurses should ensure care is person centred, undertake holistic assessments and support advance care planning, underpinned by advanced communication skills. After reading this article and completing the time out activities you should be able to:
- Outline what person-centred end of life care entails and how this approach can be applied in practice.
- Recognise the main components of a holistic assessment of a person dying at home.
- Describe the process of advance care planning and the challenges associated with this in practice.
- Understand the guiding principles of end of life care conversations and how to achieve realistic shared decisions.
- Reflect on the importance of nurses maintaining their personal well-being and discuss potential strategies they could use to strengthen self-compassion and resilience.

Introduction

The decision for a person to be cared for at the end of life in the home environment requires careful consideration by everyone involved, including the individual themselves, their family (meaning all those important to the patient), healthcare practitioners and carers. Community nurses often have a central role in the coordination of services and the utilisation of the skills and expertise available in the multidisciplinary team, which are

essential to providing person-centred care. Patients' needs are often complex, and they require compassionate and timely responses from community nurses and the wider multidisciplinary team.

At the core of effective nursing practice is the establishment of a therapeutic relationship with patients and families, which enables the nurse to have a positive effect on decision-making and patient advocacy (Adams et al 2011). During the coronavirus disease 2019 (COVID-19) pandemic there was a reduction in face-to-face home visits from GPs (British Medical Association 2020, Prvu Bettger et al 2020), putting additional pressure on community nurses, who continued to carry out palliative and end of life care in people's homes. Over this period, community nurses reported feelings of isolation in the absence of normal multidisciplinary team working (Mitchell et al 2021). At the same time, service demand in the community increased as more palliative care patients chose to remain at home (Bone et al 2020). Reasons for this included fear of infection, feeling safer at home, limits to visiting in inpatient settings and not wanting to be a burden on overstretched hospital services (Hiom 2020, Quinn-Scoggins et al 2021).

These additional demands have been challenging for community nurses; some of these issues will continue, so they need to be understood further. It is important for community nurses to consider the environmental factors that may support or hinder the provision of effective person-centred care.

Person-centred care

Person-centred care has been a long-held objective in nursing, healthcare and social care policies and practice. This concept involves positioning the patients at the centre of their care and alongside healthcare practitioners as care planners rather than passive recipients of care (Social Care Institute for Excellence 2021). Person-centred care can be described as the relationship between a healthcare practitioner and a patient and those important to them, which is based on understanding, respect, shared values and creating a space where individuals can share their experiences and perceptions of the current situation, as well as their needs and hopes (Price 2019). McCormack and McCance (2017) described person-centred practice as:

'*An approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by*

values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.'

Central to these definitions of person-centred care are effective relationships and the shared values that support these. Buetow (2016) asserted that the moral values and interests of healthcare practitioners deserve as much consideration as those of patients. For example, there may be times when practitioners cannot carry out what they believe to be ethically appropriate actions and this can cause distress, resulting in suboptimal collaboration, low job satisfaction and engagement – all of which will be detrimental to person-centred care (Lamiani et al 2017). McCormack and McCance's (2020) Person-Centred Practice Framework (Figure 1) provides a useful tool for achieving the desired outcome of a healthful culture through person-centred processes.

Many of the concepts and categories in the Person-Centred Practice Framework overlap (van der Cingel et al 2016), but they all need to be considered carefully to support person-centred care outcomes (McCormack 2020). Carvajal et al's (2019) scoping review identified that the barriers to nurses achieving person-centred care were related to: knowledge of end of life care; communication skills; coping strategies; and teamwork. Environmental factors – for example resources, the physical environment and communication among the multidisciplinary team – also need to be considered because these can support or hinder person-centred care. Some community nurses may feel unprepared to manage complex end of life care, particularly with the additional challenge of normal support services being restricted or unavailable during the COVID-19 pandemic, alongside widespread staff shortages.

To achieve person-centred care in practice, nurses need to focus on:
» The nurse-patient relationship.
» Holistic assessment.
» Shared decision-making and its role in advance care planning.

TIME OUT 1
» Reflect on your thoughts and feelings in relation to death and dying. How might these influence your practice?
» Have you encountered any environmental factors that have compromised person-centred practice? Were you able to overcome these and if so, how did you do this?

Nurse-patient relationship

The nurse-patient relationship is a core component of person-centred care. As social beings, humans need to feel a sense of connectedness with others (Rogers 1961, Gilbert 2010). To be able to listen and truly understand a patient's concerns, needs and hopes, it is important for the nurse to develop a rapport with them, which will enable a therapeutic relationship to be established. This requires significant skill and emotional investment from the nurse, who may feel vulnerable as close relationships develop with patients approaching the end of life. It involves 'being alongside' rather than 'doing for' a person who is at the end of life, which implies an equal relationship, and this level of engagement may cause discomfort.

An effective nurse-patient relationship can be achieved through authentic engagement when those involved connect on an emotional level, value and respect each other as whole human beings. To be authentic, nurses need to be honest, open and genuine, while understanding the needs of others and themselves (Bordin 1979, Heron 1999). Caring for people at the end of their life often presents challenges that nurses may feel they cannot adequately address, and in some cases the nurse may need to explain that some treatment options are not suitable or that it will not be possible to meet certain care preferences. Shared decision-making and care planning is vital to support the attainment of realistic outcomes while addressing aspects related to the patient's physical and mental well-being (Roter 2000, Reubin and Tinetti 2012).

Collaboration and equality in the nurse-patient relationship can empower individuals to have a sense of control over their treatment and care options. However, balanced against this is the need for an awareness of professional boundaries and consideration of the effect of such a relationship on the nurse's well-being.

TIME OUT 2

Think about a time when you have had a conversation with a patient about the management of their end of life care at home. Consider this interaction and note down what you did to develop a therapeutic relationship with the patient. What was effective and what could be improved? Reflect on how you felt during and after this conversation. If you could repeat this conversation, would you have done anything differently and why?

Holistic assessment

Before any shared decisions about care and treatment can be made, a holistic assessment of the patient should be undertaken, which can then be used as a basis for planning care with the patient and their family. Community nurses are in an optimal position to facilitate this assessment. To uphold the principles of person-centred care, nurses need to hear and understand the patient's 'story', including their hopes, priorities and goals.

The elements of a holistic assessment should be taken into consideration, including the overall health of the individual from a physiological, psychological, sociological, spiritual and cultural perspective. Faull and Blankley (2015) suggested that these elements need to be considered alongside knowledge of the person's disease and its anticipated symptoms, enabling timely decisions to be made about care and treatment, with appropriate involvement across services. Part of the assessment process involves identifying people's concerns, which can subsequently lead to shared decision-making and promote a forward-thinking approach. It is also beneficial to establish common priorities and expectations regarding the outcomes of treatment and disease progression (Antunes et al 2014).
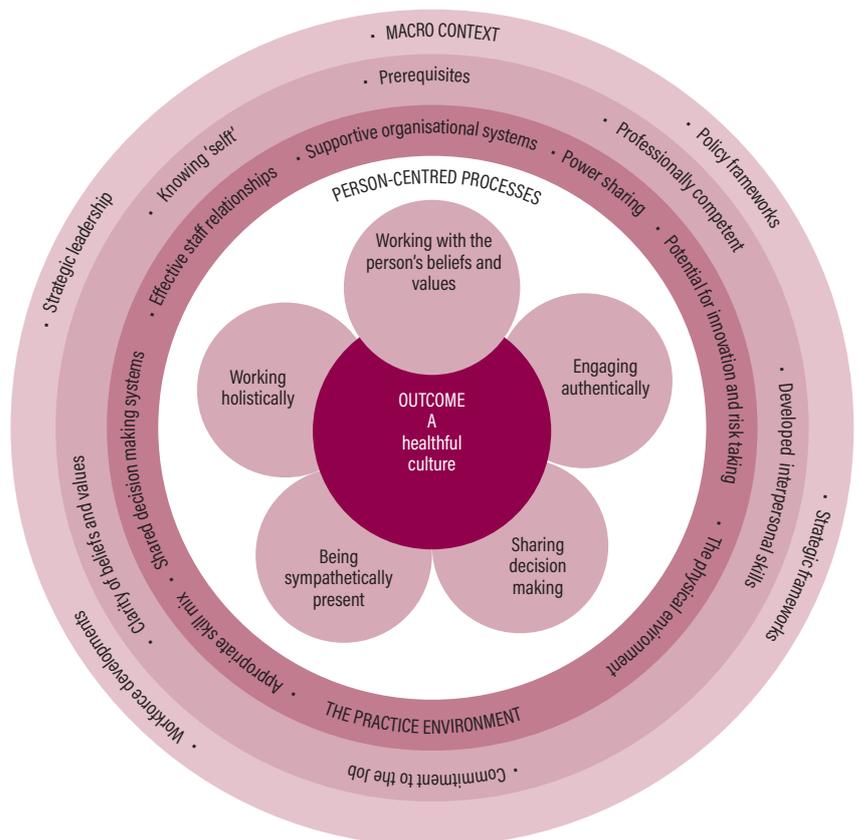
The Outcome Assessment and Complexity Collaborative (an initiative that seeks to implement outcome measures into routine palliative care) advocates several measures that

Figure 1. Person-centred practice framework

may assist healthcare practitioners to establish the pillars of the assessment process (Witt et al 2021). Such measures can be used to improve team working, drive quality improvement, deliver evidence on the effect of services, inform commissioning and achieve improved outcomes for patients. The measures developed by the Outcome Assessment and Complexity Collaborative include the following elements of palliative care practice, which should be considered (Witt et al 2021):

» The stage of the patient's condition.
» The patient's functioning.
» The patient's symptoms.
» The concerns and priorities of the patient and their carers.
» The effect of the condition and services on the patient and their family.

TIME OUT 3

Manir is 37-year-old man who lives with his partner and young children, residing temporarily in his partner's parents' house. He has lung cancer with widespread metastases with a prognosis of weeks.

You are visiting Manir to complete a palliative care assessment due to a recent deterioration in his condition. When you meet him and his family for the first time you notice he appears to have an easy-going nature and a supportive, loving family. Manir is chatty but seems reluctant to speak about his condition. You notice he appears weak, has an altered posture when walking and grimaces when he moves. However, when you initially ask about it, he jokes that it is 'part of dying'.

» What barriers may constrain the palliative care assessment, for example lack of time or environmental factors?
» How would you guide the assessment to ensure it focuses on Manir's priorities?
» Reflect on how palliative care assessments are carried out in your team – are they aligned with best practice? Check this against the National Institute for Health and Care Excellence (NICE) (2021) quality standard on End of Life Care for Adults, available at: www.nice.org.uk/guidance/qs13

Shared decision-making
The shared decision-making process can be complex and involves collaborative conversations that explore patients' preferences regarding their care and treatment. This process also requires healthcare practitioners to share their expertise and knowledge with the patient in a format that they understand, thus helping to inform their decision-making. It is important to acknowledge that at times the patient will be the expert in their condition, particularly those with long-term conditions (NICE 2022).

Applying a shared decision-making approach is challenging at the end of life because there are often significant levels of emotional distress, so the process requires not only time, but also emotional investment and energy from patients, family members and nurses (Phillips et al 2019). Many patients will involve their family in decision-making to varying degrees and this may include younger children, although they are often excluded from potentially distressing conversations. Balancing family involvement with the patient's autonomy to make decisions can present challenges (Dees et al 2013). In addition, as a coping mechanism, some patients may distance themselves from decision-making, and this needs to be acknowledged and respected by their family members and healthcare practitioners.

Healthcare practitioners have a duty to offer patients choices that are realistic, balanced and fair, which will promote and enhance autonomy and ultimately improve care quality. However, when resources are scarce, not all patient choices can be fulfilled (Zolkefli 2017). Offering choices and ensuring that healthcare practitioners respect these can contribute to a sense of personal worth for patients. At a time when an incurable condition may have limited many aspects of a person's life, enhanced self-worth and a sense of control over some aspects of their care can have a positive psychological effect on them and their family. This can only be achieved by sitting with individuals and actively listening to what matters to them (Bélanger et al 2011, Kuosmanen et al 2021).

Applying shared decision-making to advance care planning
Advance care planning is defined internationally as (Sudore et al 2017):

'A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.'

Advance care planning is integral to person-centred practice because it involves shared decision-making and enables communication about what is important to the individual with a life-limiting condition. An advance care plan includes any decision a person makes about their future care (The Gold Standards Framework 2018, NICE 2019). Box 1 shows some of the potential elements of an advance care plan.

Historically, doctors or specialist palliative care teams led advance care planning discussions; however, compromised access to these healthcare services has resulted in the opportunity and expectation that other healthcare practitioners,

including nurses, should take an increasingly proactive role in initiating advance care planning discussions (Raftery et al 2020). One advantage of nurses taking such as role is that they can simplify and explain medical terminology to patients and families, ensuring a common understanding of each patient's goals and advocating for these across the wider healthcare team (Adams et al 2011).

While initiating and facilitating conversations about advance care planning can be challenging, it can also be rewarding for healthcare practitioners. However, the policy drive to shift care from hospitals into the community (NHS England 2019, NHS Scotland 2021) amid declining numbers of community nurses (Maybin et al 2016) may leave nurses feeling they lack the time and emotional resilience to engage effectively in advance care planning conversations.

It has been identified that only 5% of healthcare practitioners feel adequately prepared to explain advance care planning options and some fear that discussing advance care planning will diminish patients' hope and increase their anxiety, although this fear is not supported by the literature (Green at al 2015, Mattes et al 2015). Despite the benefits, there are various barriers to healthcare practitioners initiating advance care planning conversations, such as lack of confidence and a concern that their prognostication might not be accurate (Blomberg et al 2020). There may also be concerns about the challenges that can arise if a patient's choices do not align with their family's preferences or the healthcare practitioner's judgement regarding appropriate care.

It can be beneficial to use the three-talk model for shared decision-making as it provides a framework for advance care planning conversations. This model comprises the following three steps (Elwyn and Durand et al 2017):

» Team talk – make patients aware that choices exist, offer support and ask them about their goals.

Box 1. Potential elements of an advance care plan

» Preferred place of care
» Preferred place to die
» Degree of interventions, including cardiopulmonary resuscitation
» Religious and spiritual beliefs
» Lasting power of attorney
» Understanding of illness and prognosis
» Preferred emergency contacts

(The Gold Standards Framework 2018)

» Option talk – discuss alternatives using risk communication principles.
» Decision talk – identify patients' informed preferences and assist them to make preference-based decisions.

TIME OUT 4

Access the Marie Curie Palliative Care Knowledge Zone (www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone), in particular the Communication and Emotional Support and High-Quality End of Life Care sections. Select an appropriate patient from your practice and, using these resources, reflect on how you could initiate advance care planning conversations with them and their family

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There is no 'one size fits all' approach that can be taken to advance care planning, since each patient, family member and healthcare practitioner will bring their own feelings and values to the conversation. Effective facilitation of such conversations takes time, skill and confidence, and can be learned and developed in practice.

While patients and families may recognise the importance of advance care planning, some may not feel comfortable initiating discussions about this with healthcare practitioners (Toguri et al 2020). The reasons for this discomfort may include the stigma around death and dying, religious beliefs, patient and family attitudes towards dying, different cultural beliefs among family members, family dynamics, and physical health issues such as confusion (Green et al 2015). As such, the nurse may need to initiate conversations about advance care planning. The advance care planning process encourages people close to the patient to understand and discuss their values, beliefs, goals, hopes and fears. This improved understanding can help the patient and their family to feel confident that all those involved in providing end of life care are striving to listen, understand and follow the patient's wishes. This may include respecting an individual's choice not to discuss their future.

At the onset of advance care planning, it is important to acknowledge that there may be differences of opinion and compromises may need to be reached, while ensuring that the patient remains at the centre of the process. A sensitive exploration of expectations and choices can establish what is most important to individuals and why (Green et al 2015).

It is essential that no false promises are made to patients and families, since these may not be achievable; for example, even if a patient wants to die at home, they may need to be admitted to an alternative place of care if suitable community care is not available to meet their

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Key points

● At the core of effective nursing practice is the establishment of a therapeutic relationship with patients and families

● Person-centred care has been a long-held objective in nursing, healthcare and social care policies and practice

● Before any shared decisions about care and treatment can be made, a holistic assessment of the patient should be undertaken, which can then be used as a basis for planning care with the patient and their family

● Healthcare practitioners have a duty to offer patients choices that are realistic, balanced and fair, which will promote and enhance autonomy and ultimately improve care quality

needs. Community nurses have extensive experience and up-to-date information about practical issues and resources, so are well-placed to advise and share their knowledge with patients and families, offering them practical solutions and options to facilitate their decision-making. Additionally, patients and families are often increasingly satisfied and accepting of decisions when a nurse is involved (Adams et al 2011).

Given that advance care planning decisions can change as a patient's disease progresses and new challenges emerge that may influence their wishes and choices (Fleuren et al 2020), engaging with specialist palliative care colleagues for advice can help to ensure that decisions are shared across relevant agencies, including GPs. Such collaborative working can contribute to improved patient outcomes (Fleuren et al 2020).

TIME OUT 5
There may be occasions when some of a patient or family's wishes cannot be met, and this may cause conflict and disagreement. For example, a patient may wish to remain at home, but their family might feel unable to cope physically and/or emotionally. In addition, healthcare practitioners may feel some of the patient's and family members' wishes are unachievable or unrealistic. Reflect on a time when this has happened in your clinical practice:
» Did you manage to achieve a resolution?
» What negotiation skills did you use?
» If no agreement could be achieved, what happened afterwards and how did this leave you feeling?

Importance of self-care for nurses
In the authors' experience, in challenging situations such as end of life care, nurses are often critical of themselves, particularly when a situation has not gone well. This can result in a lack of confidence in their ability to carry out the role.

High workloads may compound this issue and can result in high stress levels and emotional exhaustion, which may manifest in lower job performance, higher staff sickness levels, low staff retention and reduced job satisfaction (Burke 2014, Jun et al 2021).

Talking to colleagues informally and formally can assist nurses to gain a sense of perspective and balance. If available, resilience-based clinical supervision provides an opportunity for gaining such perspective and balance by focusing on the emotional systems that motivate people's responses to work situations or issues.

Resilience-based clinical supervision includes elements of mindfulness-based exercises with a view to enhancing well-being, resilience and care (Foundation for Nursing Studies 2018). Mindfulness refers to an individual's ability to remain present and fully engaged with

whatever they are doing in the moment – free from distraction or judgment, and aware of their thoughts and feelings without becoming 'caught up' in them. Its benefits are widely recognised in healthcare and broader society (Orellana-Rios et al 2018, Warth et al 2020).

Practical mindfulness-based changes that nurses could initiate may include establishing a positive morning routine, concentrating on one task at a time, taking meaningful breaks, focusing on breathing and making plans after work (Bhatti 2022). Mindfulness will not remove the challenges a nurse experiences, but it may empower them to regain some control and work effectively.

Staff well-being is recognised as an important prerequisite for person-centred care outcomes (McCormack and McCance 2017, Sizmur and Raleigh 2018). Organisational support, such as employee assistance programmes and access to resilience-based clinical supervision, is required. The Royal College of Nursing (2019, 2021) advises that community nurses should also take some responsibility for their health and engage in achieving a sustainable work-life balance, which will assist them to be compassionate towards themselves and others.

TIME OUT 6
Determine your level of self-compassion using the Self-Compassion Test, a validated tool developed by Kristin Neff that is available at: self-compassion.org/ self-compassion-test
» Think about your inner resources and your wider support networks. What self-compassion practices do you currently use and what others could you attempt to use?
» What resources does your healthcare organisation offer to support staff well-being?

Conclusion
The delivery of end of life care at home is complex, and the COVID-19 pandemic led to increased challenges for community nurses in supporting person-centred care, with an ever-changing environment and an expectation that they would continue to provide face-to-face visits for patients, including those approaching the end of life. There is a requirement for nurses to continuously develop their palliative and end of life knowledge and skills, including advanced communication skills, which may give them greater confidence to broach the subject of death and dying with patients and families. Healthcare organisations and service leads should develop policies, training and tools that support person-centred practice. Organisations should also be cognisant of staff well-being and the need to provide resources to support nurses.

TIME OUT 7

Identify how supporting end of life care applies to your practice and the requirements of your regulatory body

TIME OUT 8

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: **rcni.com/reflective-account**

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Person-centred end of life care

TEST YOUR KNOWLEDGE BY COMPLETING THIS MULTIPLE-CHOICE QUIZ

1. During the coronavirus disease 2019 (COVID-19) pandemic:

a) Service demand in the community decreased ☐

b) Fewer palliative care patients chose to remain at home ☐

c) There was a reduction in face-to-face home visits from GPs, putting additional pressure on community nurses ☐

d) All community nurses stopped carrying out palliative and end of life care in people's homes ☐

2. Person-centred care is:

a) An approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives ☐

b) Underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding ☐

c) Enabled by cultures of empowerment that foster continuous approaches to practice development ☐

d) All of the above ☐

3. What is the outcome in McCormack and McCance's Person-Centred Practice Framework?

a) A healthful culture ☐

b) A 'one-size-fits-all' approach to care ☐

c) An improvement in quality of life ☐

d) A 'good death' ☐

4. How might an effective nurse-patient relationship be achieved?

a) By recognising that the nurse is always the expert on the patient's condition ☐

b) Through authentic engagement when those involved connect on an emotional level and respect each other ☐

c) By implementing a 'top-down' hierarchical approach to care, in which the nurse is positioned above the patient ☐

d) Through the provision of task-focused nursing care ☐

5. Holistic assessments:

a) Can be used as a basis for planning care with the patient and their family ☐

b) Should not be facilitated by community nurses ☐

c) Are unrelated to person-centred care ☐

d) Should only consider the physical health of an individual

6. Which statement is false?

a) Applying a shared decision-making approach is challenging at the end of life because there are often significant levels of emotional distress ☐

b) Some patients may distance themselves from decision-making and this needs to be acknowledged and respected by their family members and healthcare practitioners ☐

c) Healthcare practitioners have a duty to ensure that all patient choices and preferences are always met ☐

d) Many patients will involve their family in decision-making to varying degrees ☐

7. One potential element of an advance care plan is:

a) Preferred place to die ☐

b) Degree of interventions, including cardiopulmonary resuscitation ☐

c) Lasting power of attorney ☐

d) All of the above ☐

8. Which of these is not one of the steps of the three-talk model?

a) Team talk ☐

b) Self-talk ☐

c) Option talk ☐

d) Decision talk ☐

9. Which statement is true?

a) Only doctors or specialist palliative care teams can initiate advance care planning discussions ☐

b) Most healthcare practitioners feel adequately prepared to explain advance care planning options ☐

c) Nurses may need to initiate conversations about advance care planning ☐

d) A standardised template for advance care planning must be developed to reduce individual differences ☐

10. What does resilience-based clinical supervision entail?

a) Focusing on the emotional systems that motivate people's responses to work situations or issues ☐

b) Talking to colleagues informally ☐

c) Enhancing access to employee assistance programmes ☐

d) Exploring strategies for reducing staff sickness levels ☐

This activity has taken me ___ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

Excellent ☐   Good ☐   Satisfactory ☐   Unsatisfactory ☐   Poor ☐

As a result of this I intend to: _____

_____

_____

_____