Views and experiences of nurses and health-care assistants in nursing care homes about the Gold Standards Framework

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Abstract

Aim: To explore the views and experiences of nurses and health-care support staff about the use of the Gold Standards Framework (GSF) for end-of-life care (EoLC) for older people in nursing care homes (NCHs) with GSF accreditation. **Methods**: A qualitative descriptive study was conducted with three purposively selected NCHs in London. Individual interviews were conducted with NCH managers (*n*=3) and in each NCH, a focus group was conducted with registered nurses (RNs) and health-care assistants (HCAs): focus group 1, *n*=2 RN, *n*=2 HCA; focus group 2, *n*=2 RN, *n*=3 HCA; focus group 3, *n*=3 RN, *n*=3 HCA. Interviews were audio-recorded, transcribed and analysed using framework analysis. **Findings**: Three core themes were identified: (i) a positive regard for the GSF for care homes (GSFCH); (ii) challenges around EoLC for older people; and (iii) difficulties in using the GSFCH. **Conclusions**: RNs, HCAs and managers regarded the training and support afforded by the GSFCH programme to inform EoLC for older residents positively. The framework has the potential to promote a coordinated approach to EoLC for older people. In the post accreditation period, there is a need for ongoing support and development to help embed the key tenets of the GSFCH in the culture of caring.

Key words: End-of-life care ● Gold Standards Framework ● Older people ● Nursing care homes

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End-of-life care (EoLC) is a key public health challenge (Davies and Higginson, 2004; Froggatt and Payne, 2006; Department of Health (DH), 2008). Much of the world's population is living longer (Gomes and Higginson, 2008; Hall et al, 2011a) with complex health and social-care needs (Hughes-Hallett et al, 2011). With increasing frailty and complex medical problems, many older people are faced with the need to move to a long-term care facility such as a nursing care home (NCH) (Froggatt and Payne, 2006). Approximately 80 000 people die in care homes (those providing nursing as well as personal care) in England each year (DH, 2008). It is incumbent upon all care homes to deliver high-quality EoLC for older people (DH, 2008; Waldrop and Kirkendall, 2009; British Geriatrics Society, 2011).

One quality improvement programme for EoLC is the Gold Standards Framework (National Gold Standards Framework Centre, 2010), which is used in a variety of care settings including care homes. The Gold Standards Framework for Care Homes (GSFCH) programme aims to enable the provision of high-quality EoLC for residents and their families/significant others (National Gold Standards Framework Centre, 2010). The framework focuses on communication, coordination, control of symptoms, continuity of care, continued learning, carer support, and care of the dying. Care homes pay a fee to undertake the GSFCH training programme which includes having a designated training facilitator, learning resources, and training workshops. Care homes are assessed against 20 standards of best practice to achieve the GSF accreditation quality hallmark award. Re-appraisal occurs annually and re-accreditation every 3 years.

Studies of the GSFCH programme have examined care provision, pre- and post-commencement of the programme. Key findings are that the GSF enhances communication within and outside of the care facility (Ashton et al, 2009; Badger et al, 2009, 2012; Hewison et al, 2009; Hockley et al, 2010; Watson et al, 2010), enhances nurse confidence to assess physical and emotional needs of residents, and helps achieve better symptom control (Ashton et al, 2009; Badger et al, 2009; Hewison et al, 2009; Hockley et al, 2010; Watson et al, 2010). Nursing care home staff are better equipped to discuss 'do not attempt resuscitation' (DNAR) orders with residents and families following implementation of the GSFCH programme, and there is improved documentation of DNAR orders (Badger et al, 2009; Hockley et al, 2010; Watson et al, 2010). There is also a reduced need for hospital admissions when residents are dying (Watson et al, 2010). To date, little published research has investigated EoLC in NCHs in the post-accreditation period (Finucane et al, 2013). Understanding the views and experiences of staff using the GSF in NCHs that have achieved GSF accreditation is needed to inform ongoing review of how best to enable NCHs across the sector to

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Table 1. Profile of nursing care home (NCH) sites and participants

Nursing home	Number of beds	Gold Standard Framework (GSF) accreditation date	Individual interviewee information	Number of nursing staff (RNs and HCAs) participating in focus group	Length of time RNs and HCAs have been employed at NCH
1	93	June 2009	Manager of nursing home Involved in training and accreditation process for GSFCH	4 (2 RN, 2 HCA)	7 months–7 years
2	37	June 2010	Manager of nursing home Involved in training and accreditation process for GSFCH	5 (2 RN, 3 HCA)	1.5 years–11 years
3	51	January 2011	Deputy Manager of nursing home Involved in training and accreditation process for GSFCH	6 (3 RN, 3 HCA)	1 years–6 years

RN = Registered nurse, HCA = Health-care assistant

provide consistently good EoLC for older adults.

Aim and objectives

The aim of the study was to investigate the views and experiences of RNs and HCAs using the Gold Standards Framework in NCHs post-GSF accreditation. Specific objectives were to explore:

- Their experiences of using the GSFCH for EoLC for older adults
- The benefits and challenges of using the GSFCH.

Method

This was a qualitative descriptive study (Sandelowski, 2000). Three NCHs were purposively sampled from 19 in south-east London that, at the time of the study, had GSF accreditation and registration to care for older adults; this information was sourced from the local GSFCH facilitators. To maximise the opportunity to gain insight about participants' views and experiences, homes that had been using the framework for at least 6 months post-accreditation were targeted. The NCHs included in the study were local specialist community palliative care teams with access to a common service of support for palliative care. The NCHs varied in size from small (37 beds), to medium (51 beds) and large (93 beds).

The managers of the three NCHs were recruited to the study. With a view to recruiting four to six staff in each NCH to participate in a focus group, a sampling frame of all RNs and HCAs in each NCH was compiled. Potential participants were identified by the NCH managers working at the time when the researcher was meeting staff to explain research participation. The principal researcher (and first author on this article, AN) then met with each potential participant to explain the study. Potential participants had 5 days to make an informed decision and all agreed to participate. RNs and HCAs were recruited in order to capture the perspectives and experiences of those caring for older people in NCHs on a daily basis. *Table 1* presents a profile of each NCH and the participants of the study.

RNs and HCAs in each NCH took part in a focus group interview: focus group 1, *n*=2 RN, *n*=2 HCA; focus group 2, *n*=2 RN, *n*=3 HCA; focus group 3, *n*=3 RN, *n*=3 HCA. The manager of each NCH was interviewed individually (*n* =3) to enable full and frank conversations and reduce the potential influence of any perceived hierarchies. An observer, a palliative care clinical nurse specialist, was present at the focus groups to make field notes about the topics discussed and the group dynamics. The principal researcher also has past experience as a palliative community nurse specialist and engagement with NCHs using the GSFCH, which may have unknowingly influenced the researcher. It was impossible to remove this portfolio of experience, knowledge, assumptions and potential biases from the research process, but the authors were able to acknowledge this and make the research more sensitive to aid a full understanding of the issues discussed (van Manen, 1990). The principal researcher maintained a diary, with field notes recorded following all visits to the research sites and after each interview to assist in gaining a full narrative about the views and experiences of the staff. The researcher and the observer were not known to the research sites and participants.

Data collection

Questions posed in the interviews focused on:

- What are staff experiences of caring for residents in the NCH near to the end of life?
- What are the challenges of caring for these residents?

- What has been helpful about the GSFCH programme for EoLC for older residents?
- What has been challenging or difficult when implementing the GSFCH?
- What could improve use of the GSFCH?

The interview questions were reviewed by four palliative care clinical nurse specialists, who advised that no refinements were required. All interviews were conducted by the principle researcher in the NCHs.

Ethical considerations

Ethical approval for the study was obtained via the National Research Ethics Service Committee South Central – Berkshire in May 2011 (REC reference 11/SC/0132). The principles of informed consent, protection from harm, confidentiality, anonymity and information management were adhered to throughout the research process.

Data analysis

The interviews were transcribed verbatim and rechecked by the principle researcher listening to each interview. The data were analysed using framework analysis (Ritchie and Spencer, 1994), and shown in *Figure 1*. This method comprises five stages: (i) familiarisation, (ii) identifying a thematic framework, (iii) indexing, (iv) charting and (v) mapping and interpretation. The researcher was immersed in all interview transcripts along with the observation notes and the researcher's diary to help develop a narrative about the experiences of research participants. Data analysis activities were discussed and verified in a series of one-to-one meetings between the researchers. A limitation of the analysis process was that the study time scale did not permit validation of the core themes that emerged following data anaylsis by the participants. Analysis identified three core themes, which are presented below.

Findings

There was synergy in the findings for RNs, HCAs and managers in the three NCHs with regards to their views on the GSFCH.

Positive experiences of the GSFCH in EoLC for older residents

Positive experiences of RNs and HCAs focused on five key areas: confidence in managing EoLC; improved communication skills and knowledge; advance care planning; recognising end of life and managing the dying process; and symptom control.

Participants spoke of being more confident and expressed positive feelings in caring for residents at the end of life. These were described as 'increased confidence', 'a good experience' and 'doing their best'. They spoke of a more holistic approach to their care of residents and families, with attention to physical, psychological and spiritual care and support:

> **'When you do the training you can give moral support, communication, bereavement, there's a lot of difference...' (Manager)**

Participants in NCHs 1 and 2 spoke of caring for residents as 'caring for their own family'. There were descriptions of how the NCH had become the residents' home and they were now part of their family:

> **'I say to staff... look after this woman as you would your grandmother [or] mother' (Manager)**

Being more confident and having greater knowledge about EoLC was discussed by participants, specifically about their communication skills, involvement in advance care planning, recognition of dying and management of the dying process, and symptom control. Participants spoke of how the GSFCH programme, and specifically staff training, had enhanced their communication skills. This included improved completion of NCH records, out-of-hours forms and advance care plans as well as their communications with residents, families and health professionals external to the NCHs.

Advance care planning was regarded positively, with participants discussing how they valued having clear records about residents' resuscitation status, preferred place of death and arrangements post-death. Discussions on this topic included staff feeling more able to communicate about EoLC issues, and engaging earlier with planning that involved residents, families and the multiprofessional care team. Participants also reported being able to talk more easily with clinicians, relatives and residents about EoLC and care planning as well as offering bereavement support:

> **'We are confident now to involve the family; again we can take the discussion and can involve the family and the GP' (RN)**

> **'...involving the family in the end care and... making the decision even as much earlier as we can... in their care and treatment and involving and keeping family and other health care professionals... it's more easy for us now' (RN)**

Several participants spoke of greater confidence in recognising that residents are deterio-

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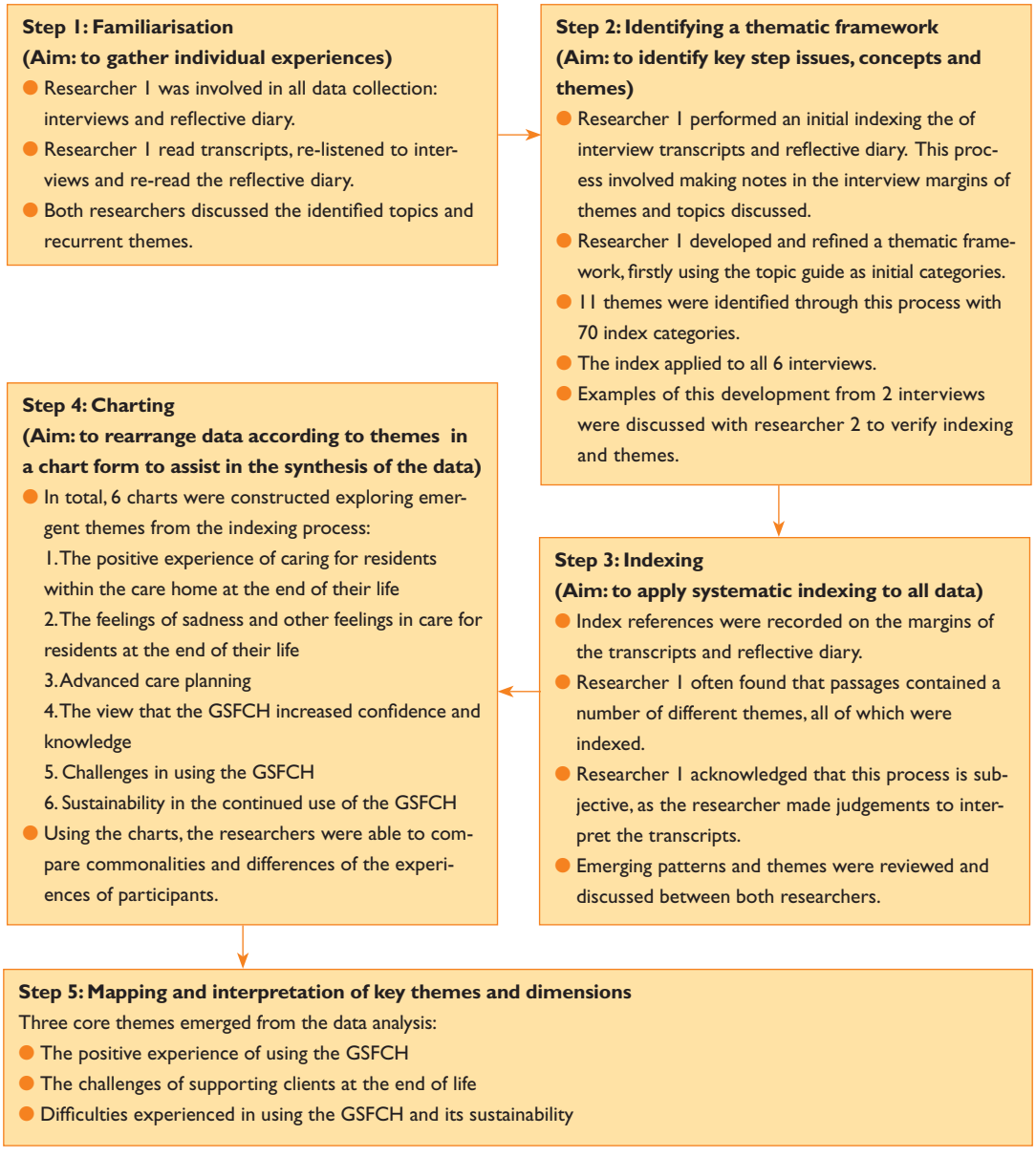

Figure 1. Data analysis process using the 'framework method'
(Ritchie and Spencer, 1994)

rating and dying, and in managing the care process. They shared that reflecting on residents' care and changes to their condition was facilitated by regular in-house meetings and use of the GSF coding system:

> **'You understand what the end of life means, how you should treat [patients] with respect... you understand their condition is deteriorating'** (RN)

Better symptom control was discussed by participants in NCHs 2 and 3; for other participants achieving symptom control was identified as an ongoing challenge. Pain was the main symptom that participants reported having gained most confidence in being able to assess and manage:

> **'We know exactly what to do and we have more confidence... we now have our own syringe driver and feel confident in ordering the end-of-life medications from the GP...'** (RN)

In all interviews, the GP was identified as the health professional who assisted most with management of residents' acute symptoms.

Challenges of caring for older residents at the end of life

While participants all reported positive views and experiences of the GSFCH programme, they also shared some challenges in caring for residents at the end of life. These centred around how to enable a 'good death', communication with residents and relatives, symptom control, and co-ordinat-

ing care at the end of life.

Participants spoke of their commitment to facilitating a 'good death' for residents. Challenges for some staff included being able to recognise deterioration and how to define 'end of life'. Communication was a key challenge that participants also spoke about. In the individual and focus group interviews, communicating with relatives about EoLC planning and residents' deterioration were the most commonly discussed challenges. This was particularly the case when family members disagreed with each other and/or the resident regarding care and decisions about care. Participants spoke specifically of the challenge arising when family members were 'not ready', 'not accepting', or 'not understanding' about approaching death:

> **'One thing that I find the great challenge is with relatives, and it's about accepting the change of the resident. You do find some family members that are in denial basically.' (HCA)**

> **'We had problems like relatives challenging their [the patient's] decision… before the worst happens you have to explain...' (RN)**

Communicating with residents about advance care planning was discussed as a challenge for the focus group participants in NCH 3; nurses discussed concerns that if planning for the end of life was discussed with residents, residents would 'give up'. Another issue discussed was how best to communicate with residents about EoLC when there is reduced mental capacity e.g. due to dementia.

Coordinating care within the multidisciplinary team to support residents at the end of life was described as a challenge on occasions for some participants in NCHs 1 and 2. For example, when residents do not have full mental capacity, so their wishes are not known. In one account from NCH 1, a resident was transferred to hospital where they died; the NCH staff knew that the resident wished to be buried and spoke of feeling sad that the resident had died in hospital but happy that they were able to talk with the social worker about the resident's wish to be buried.

In all three NCHs, participants communicated that a 'good relationship' with their team, and in particular with GPs, were pivotal to managing their roles. Participants described how they were able to contact GPs to discuss communication difficulties with relatives and all had access to GPs outside their regular visits to the NCHs. It was also evident during the interviews that NCH managers play a key role in leading and managing challenges around EoLC.

Continuing to use the GSFCH and sustainability in the NCHs

For NCHs 1 and 3, staff felt that continuing to use the GSFCH presented no problems. Participants in NCH 2 spoke of the amount of time required to complete the paperwork associated with the GSFCH; this was particularly the case when the NCH was working towards accreditation.

Knowing when to commence and review documentation used to care for residents in the last days of life was reported as a difficulty for some nursing staff. This was particularly pertinent in situations where residents were dying from a non-malignant illness. Another debate in two of the focus groups centred on what they called the 'legality' of the GSF paperwork and advance care planning tools. For example, one focus group debated the usefulness of the framework as they were unclear what documentation could be used to ensure that families understood when a patient's wish was not to be sent to hospital when nearing death.

The principle researcher noted in the reflective diary that during the period of data collection all three NCHs were working on documentation to maintain GSFCH accreditation. Staff noted that the 'paperwork is now less' complared to when the NCHs were working towards becoming accredited. Continuing education and support from community palliative care teams, and in particular GSFCH facilitators, were regarded positively by participants in the three NCHs. All three NCHs were engaged with regular staff training about palliative and EoLC and continued input from the GSFCH facilitator was well received. NCH 3 described their ongoing working with their GSFCH facilitator whom they valued and who continued to assist with staff updates in addition to providing support to staff experiencing difficulties around EoLC issues. No one spoke of wanting to discontinue use of the GSFCH; indeed all three NCHs were working towards their annual GSFCH accreditation.

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Discussion

In this study, RNs, HCAs and managers were generally positive about the GSFCH and the continued use of this framework to help achieve good EoLC for residents. Participants were of the opinion that the programme had increased staff confidence to communicate about and manage EoLC for older residents. This finding concurs with the survey of UK NCHs by Badger et al (2009) and the interviews with NCH staff and relatives by Hall et al (2011b). In the study reported in this paper, staff described how the GSFCH training had helped develop their skills in communicating

'The study identified that the GSFCH programme helped staff to care for residents at the end of life and helped facilitate a 'good death'.'

with residents about their care and their preferred place of death, which helped avoid unnecessary hospital admissions. An evaluation of the GSFCH by Hockley et al (2010) reported an apparent reduction in unnecessary hospital admissions. There is a need for further research to investigate the impact of the GSFCH programme on outcomes for residents, families, staff and NCHs.

Support from and effective communication with hospital and primary health-care professionals emerged as significant for EoLC for residents. Participants spoke of how hospital teams had assisted residents to remain in the NCH rather than return to hospital to die when this was feasible and the preferred choice of residents; this was facilitated by clear communication about prognosis and DNAR discussions with residents' GPs. The key role of the GP in EoLC planning with residents and their families was also highlighted; an example given was GPs leading discussions about EoLC DNAR. Two of the NCHs notably had telephone support from their GPs out of the normal visiting sessions to the homes and this was particularly helpful when residents deteriorated. The importance of collaborative working with GPs for good EoLC for older people in NCHs has been reported in other research (Hall et al, 2011b; Seymour et al, 2011; Badger et al, 2012). A review of interventions for improving palliative care for older people living in NCHs by Hall et al (2011a) argues that development of multidisciplinary teams in addition to staff training is essential.

In the present study, the support of NCH mangers was described by staff as essential to help them address challenges encountered in providing EoLC. Published literature about the GSFCH and other quality improvement frameworks has highlighted a stable and effective management structure and sound leadership as requirements for successful implementation (Hewison et al, 2009; Watson et al, 2010; Hockley et al, 2010; Seymour et al, 2011; Finucane et al, 2013). The nurse managers in turn spoke highly of the training they had received when undertaking the GSFCH programme and the support of their local community palliative care teams and the GSFCH facilitators.

When focusing on the challenges of using the GSFCH, the amount of time required for documentation was raised. King et al (2005) and Hall et al (2011b) also highlighted how staff identified problems with an increased workload when implementing the GSF. Earlier research (King et al, 2005; Mahmood-Yousuf et al, 2008) investigating the introduction of the GSF in GP practices found that administration time was an important factor for the successful implementation of the GSF. On a positive note, participants in this study were of the view that completion of paperwork had become easier post-accreditation. The legality of advance care plans and who is responsible for DNAR decision-making was discussed by some participants. Before implementation of the GSF it was reported that DNAR decision-making did not take place consistently, resulting in some dying residents being sent to hospital although this may not have been the residents' preferred choice.

The difficulty of recognising deterioration, the palliative care status of residents, and estimating the survival time of residents was discussed by some participants. Further development of staff skills and knowledge to assess and manage symptoms such as pain was also flagged, which concurs with research by Goddard et al (2011). The complexity of chronic disease management of older people is also acknowledged as a challenge for health professionals (DH, 2010).

Nevertheless, it is incumbent upon NCHs to have a nursing workforce that is able to 'identify, assess and plan care for residents who are approaching the end of life' (DH, 2008: 160). Further consideration of how best to achieve and sustain this is required. A systematic review by Coventry et al (2005) aimed to identify tools and predict variables that might aid clinicians to estimate survival and assess palliative care status in non-cancer patients. They concluded that it was not possible to identify a specific tool that could be used meaningfully for a non-cancer population, due to the unpredictability of illness progression and deterioration. Coventry et al (2005) discussed the need for the development of a simple, well-evaluated prognosis model that could provide clinicians with an objective measure. In this regard, evaluating the effectiveness of the GSFCH coding tool which is used by nursing staff to assess residents' palliative care status warrants further investigation.

Limitations

This study sought to capture participants' views and experiences. It is limited by a small sample size and a sampling approach that was not able to include residents and their families/significant others and other members of the multidisciplinary team. It is acknowledged that there are limitations to framework analysis; however, it was a successful method for the novice principal researcher of this study to analyse the data systematically and with transparency and rigour. Use of framework analysis has also been defended in other studies (Stewart et al, 2011; Ward et al, 2013). The authors acknowledge that not all positive views about EoLC in the participating NCHs can be attributed to the GSFCH programme.

Conclusions

At the time of this study, limited research had focused specifically on the views and experiences of staff using the GSFCH in NCHs post-accreditation. Some research to investigate sustainability of the GSFCH in NCHs has since been reported (Finucane et al, 2013) and further work is needed. In this study RNs, HCAs and managers were supportive of the GSF and what it has to offer to help provide high-quality EoLC for older NCH residents. The study identified that the GSFCH programme helped staff to care for residents at the end of life and helped facilitate a 'good death'. Challenges were also identified, which highlight the importance of ongoing support for NCHs post-accreditation if good EoLC is to become embedded in the culture and daily practice of NCHs. This support should address areas such as recognising end of life, communication skills with residents and families about advance care planning, managing EoLC for residents with dementia, and symptom assessment and management. Research on the introduction of the GSFCH in NCHs (Hockley et al, 2010) highlighted the need for local authorities and NCH management to invest in support and development to ensure the programme is properly embedded within the NCH culture. This paper contributes to the discussions on EoLC in ageing societies and discussions about the future implementation of the GSFCH. To make a sustainable contribution to EoLC for older adults in NCHs, education, training and ongoing review and evaluation of the GSFCH must be embedded in the culture of these facilities. IJPN

Declaration of interests
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