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# Communicating risk in dementia care: Survey of health and social care professionals

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## Abstract

Supporting people to live at home in line with community care policies requires increasing attention to assessing, communicating and managing risks. There is a challenge in supporting client choices that include risk-taking while demonstrating professional accountability. Risk communication becomes increasingly important with the need to engage clients and families in meaningful shared decision-making. This presents particular challenges in dementia services. This survey of risk communication in dementia care was administered to all health and social care professionals in community dementia services in Northern Ireland: June–September 2016. Of 270 professionals, 70 questionnaires were fully completed, with 55 partial completions. Scores on the Berlin Numeracy Test plus Schwartz items was low-moderate (mean 2.79 out of 7). This study did not find a significant association between numeracy and accurate perceptions of risk likelihoods in practice-based scenarios. Although 86% reported using numeric information in practice (mostly from assessment tools), respondents rarely communicated themselves using numbers. As in other domains, participants' responses were widely variable on numeric estimates of verbal terms for likelihood. In relation to medication side effects, few participants provided responses that were concordant with those in the guidance of the European Union. The risks most commonly encountered in practice were (in rank order): falls, depression, poor personal hygiene, medicines mismanagement, leaving home unsupervised, financial mismanagement, malnutrition, swallowing difficulties, abuse from others, risks to others, home appliance accidents and refusing equipment. Respondents generally overestimated the likelihood of serious harmful events by approximately 10-fold (having a missing person's report filed with the police; having a fall resulting in hospitalisation) and by approximately double (being involved in a car accident; causing a home fire), and with wide variation between respondents. There is potential in icon arrays for communicating risks. Risk literacy among dementia care practitioners needs to be developed.

KEYWORDS

assessment, communication, dementia, numeracy, risk, shared decision-making

## 1 | INTRODUCTION

Communication about risks in community care is challenging, but is essential if individuals and families are to be educated and empowered to make good care decisions (Bunn et al., 2017). Professionals, family members and those cared for may conceptualise risks differently (Nay et al., 2015). People may be prevented from unnecessary admission to hospital or long-term care (Thwaites, Glasby, le Mesurier, & Littlechild, 2017) by greater attention to "managing risk" at home.

Community dementia care requires "proportionate, measured and enabling approaches to risk" (Department of Health, 2010, p. 6) to enable independent living (Heward, Innes, Cutler, & Hambidge, 2017). Shared decision-making—often within the context of "assessment" (Taylor, 2012)—presents challenges in managing risk (Department of Health, 2007; Stevenson & Taylor, in press b). The concept of "enablement" includes some balance of potential benefits from taking risks against possible harm (Taylor, 2006). Effective risk management requires clear risk communication, not least with the development of clinical and social care governance (Taylor & Campbell, 2011) and respect for client choice.

"Risk literacy" (Cokely, Galesic, Schulz, Ghazal, & Garcia-Retamero, 2012; Gigerenzer, 2014) is increasingly recognised as integral to health literacy and shared decision-making in health and social care (Ahmed, Naik, Willoughby, & Edwards, 2012; Elwyn et al., 2004; European Medicines Agency Benefit-risk Methodology Project Team, 2011; Lewiecki, 2010; Taylor, 2017a; Zipkin et al., 2014). Including people with dementia in decision-making contributes to quality of life (Menne, Judge, & Whitlatch, 2009), personhood (Fetherstonhaugh, Tarzia, & Nay, 2013) and autonomy (Samsi & Manthorpe, 2013). However, there are many challenges in discussing risks (Miller, Whitlatch, & Lyons, 2016; Sinclair, Oyebode, & Owens, 2016; Taghizadeh Larsson & Osterholm, 2014).

Effective risk communication requires an understanding of how risks are conceptualised (Moreland, Raup-Krieger, Hecht, & Miller-Day, 2013). Individuals with dementia and family carers may conceptualise risk more as action or consequence than as likelihood (Stevenson & Taylor, 2016; Stevenson, Savage, & Taylor, in press). Professionals deal with uncertainties where outcomes (e.g. getting lost) may be better known than their probability of occurrence (Mousavi & Gigerenzer, 2014; Stevenson & Taylor, in press a).

Different formats for communicating likelihood of harm—including verbal (e.g. likely/rare or high/medium/low), numeric (percentages, frequencies and probabilities) and visual (graphs, tables and pictorial representations)—vary in effectiveness. Practitioners seem to prefer verbal descriptors, such as ordinal scales (low, medium, high) or terms such as "small increased risk of," rather than numeric likelihoods (Stevenson & Taylor, in press a). Verbal expressions of likelihood are widely used (Renooij & Witteman, 1999) but may be more ambiguous (Bocklisch, Bocklisch, & Krems, 2012; Brun & Teigen, 1988; Lipkus, 2007), particularly in the correspondence between numeric values and verbal expressions (Theil, 2002; Visschers, Meertens, Passchier, & De Vries, 2009). Use of verbal descriptors to present side effects of medications may lead to overestimating risks (Büchter, Fechtelpeter, Knelangen, Ehrlich, & Waltering, 2014; Knapp, Raynor, & Berry, 2004; Peters, Hart, Tusler, & Fraenkel, 2014).

**What is known about this topic**

- Supporting people with dementia to live at home is raising increasing concerns about risk.
- Shared decision-making requires increased attention to communicating risk.
- Research is inconclusive about the merits of verbal, numeric and visual risk communication.

**What this paper adds**

- Health and social care professionals make extensive use of numeric information although they more often communicate risk information using words.
- Professionals frequently overestimate how often risks with severe outcomes occur.
- Verbal descriptors for numeric likelihoods of possible harm are widely interpreted.

Numeric formats are more precise than verbal and allow for calculations (Akl et al., 2011; Renooij & Witteman, 1999) although individuals with low numeracy skills may have comprehension difficulties (Bodemer, Meder, & Gigerenzer, 2014; Ciampa, Osborn, Peterson, & Rothman, 2010; Peters et al., 2006). Low numeracy has been associated with reduced understanding of health risks (Reyna, Nelson, Han, & Dieckmann, 2009; Rothman, Montori, Cherrington, & Pignone, 2008); increased susceptibility to framing effects (LaVallie, Wolf, Jacobsen, Sprague, & Buchwald, 2012); and avoiding involvement in shared decision-making (Galesic & Garcia-Retamero, 2011). Optimal risk communication methods may depend on numeracy skills (Fagerlin, Ubel, Smith, & Zikmund-Fisher, 2007). Frequency formats have shown robust effects in improving understanding (Akl et al., 2011; Brase, 2008; Galesic, Gigerenzer, & Straubinger, 2009; Knapp et al., 2009), although individuals with cognitive impairments may experience difficulties with numeric risk data (Martini, Domahs, Benke, & Delazer, 2003; Pertl et al., 2014). Visual displays of risk information—such as graphs, charts and icon arrays—seem to enhance understanding of probabilistic information (Edwards, Elwyn, & Mulley, 2002; Galesic, Garcia-Retamero, & Gigerenzer, 2009; Okan, Garcia-Retamero, Cokely, & Maldonado, 2012), although the format has also been found to influence risk perception (Hawley et al., 2008; Schapira, Nattinger, & McAuliffe, 2006; Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010). Individual differences in numeracy (Brown et al., 2011) and graph literacy influence effectiveness of visual aids (Gaissmaier et al., 2012; Galesic & Garcia-Retamero, 2011; Okan, Garcia-Retamero, Galesic, & Cokely, 2012). Professionals in dementia care see potential in visual forms of risk communication (Stevenson & Taylor, in press a) but there is no clear preference regarding type.

Reasonably accurate estimations of likelihoods are important to ensure proportionate responses to risk. Inflated estimates of how often highly adverse outcomes occur could lead to unnecessarily risk-averse approaches to care. Dread risks—regarded as low-probability, high

consequence events, associated with fear and avoidant behaviours (cf. Gigerenzer, 2004)—are prone to overestimation bias (Lerner, Gonzalez, Small, & Fischhoff, 2003; Slovic & Peters, 2006). "Dread risks" in dementia might include serious outcomes such as causing a fire in the home or being involved in a road traffic collision. Lower numeracy is associated with greater estimation error and an overestimation of risk (Davids, Schapira, McAuliffe, & Nattinger, 2004; Gurmankin, Baron, & Armstrong, 2004; Låg, Bauger, Lindberg, & Friborg, 2014).

### 1.1 | Aims of this study

The survey aimed to: (1) describe the use of numeric data and numeracy levels in dementia care; (2) explore variability in understanding and use of verbal and numeric expressions of risk likelihoods; (3) establish a rudimentary estimate of the frequency of 16 major risks in community dementia care teams; (4) measure accuracy of perception of frequency of risks having severe outcomes against recorded data; (5) model and explore experience, concern and numeracy as predictors of accuracy of perception of frequency of risks having severe outcomes; (6) investigate views on visual aids for communicating risk likelihoods; and (7) identify practice issues in risk communication relating to people with dementia living in the community.

## 2 | METHODOLOGY

### 2.1 | Measures and procedure

An online survey was administered to all health and social care professionals in community dementia care in Northern Ireland using Qualtrics software. Selection of items, their terminology and scale anchors were informed by concepts of risk and practice issues identified in qualitative studies and a literature review (Stevenson, McDowell, & Taylor, 2016; Stevenson et al., in press; Stevenson & Taylor, 2016). Where appropriate, questions were presented as practice scenarios to ensure relevance.

#### 2.1.1 | Use of numerical data in practice

Participants selected from a list of 10 items which included clinical assessment tools, likelihoods of medication side effects and incident reports. Participants were invited to state any other forms of numeric data they used in practice.

#### 2.1.2 | Numeracy

The *Berlin Numeracy Test—Adaptive Version* (BNT) (Cokely et al., 2012; Garcia-Retamero & Cokely, 2017; Ghazal, Cokely, & Garcia-Retamero, 2014) was used plus three items from Schwartz, Woloshin, Black, and Welch (1997) were added to increase discriminability of scores. The BNT is validated for prediction of risk literacy, defined as the ability to accurately interpret and use information about risks (Cokely et al., 2012). Scores were calculated as number of correct responses up to a maximum of 7.

#### 2.1.3 | Numerical understanding of verbal probability expressions

Participants were given verbal expressions of risk framed using the European Union (EU) guidance (European Commission, 2009; European Medicines Agency, 2016) for communicating medicine risks (very common [≥1/10]; common [≥1/100 to <1/10]; uncommon [≥1/1,000 to <1/100]; rare [≥1/10,000 to <1/1,000]; very rare [<1/10,000]). Participants were provided with two statements about the probability of medication side effects ("nausea is a *common* side effect of medication A; It is *rare* for people who take medication A to have a stroke") and were asked to estimate how many out of 1,000 patients would experience the side effect. To assess general concordance between participants' estimates risk probabilities, participants' numerical probability estimates were categorised according to the risk probabilities that accompany each verbal descriptor in the EU Guidance.

#### 2.1.4 | Verbal understanding of numerical probabilities

Participants were asked how they would communicate to a patient using the five EU verbal descriptors regarding a medication side effect that was estimated to occur in 21 out of 1,000 patients.

#### 2.1.5 | Subjective judgements of probability

Participants were provided with two case descriptions and were asked to make a judgement of level of risk. In one case, a participant was asked to judge the risk of a client falling (on a scale of low/medium/high) based on information including falls history, co-morbidities and an assessment score. In the other, respondents were asked to describe a client's risk of having an accident in the home (using a six item verbal scale from "very unlikely" through to "very likely") based on history of similar incidents.

#### 2.1.6 | Use of transparent risk communication

Participants were provided with a graphical presentation (line graph) of a patient's verbally aggressive outbursts in two weeks prior to and two weeks following the trial of a new intervention. Participants selected from five alternatives for communicating this information to clients or colleagues: absolute risk reduction ("reduced from 12 to 6 instances per week"); two relative risk reduction statements (the intervention "halved" or "reduced aggressive instances by 50%") and three verbal statements with no numeric references ("reduced," "moderately reduced" and "substantially reduced" the number of instances).

#### 2.1.7 | Estimates of frequency and concern for dementia care risks

Respondents were asked to estimate the frequency of occurrence (out of 100 patients coming to their team) of 16 dementia risk factors

identified in an earlier qualitative study (Stevenson & Taylor, in press a) based on their working experience. Participants rated their levels of concern for each risk on an 11-point scale (0–10; zero = "not concerning at all"; ten = "extremely concerning").

### 2.1.8 | Accuracy of perception of frequency of risks having severe outcomes

Respondents were asked to estimate how many individuals with dementia (out of 1,000) they would expect to experience four severe, low-probability risk outcomes within the next 12 months: (1) causing a home fire; (2) driving collision; (3) hospitalised after a fall; and (4) having a missing person's report filed. Accuracy of professionals' estimates was judged against data on frequency of risks having severe outcomes: (1) records on accidental dwelling fires (Northern Ireland Fire and Rescue Service, 2014); (2) driving collisions involving over 65s (Police Service of Northern Ireland, 2015); (3) hospitalisation following over 60s population (Department of Health [Belfast], 2014); and (4) police missing person records in one United Kingdom policing area (Bantry White & Montgomery, 2015). Prevalence of these incidents among the population of interest was based on an estimated dementia population of 19,765 in Northern Ireland (Alzheimer's Society, 2014). Incidence of falls in the dementia population was assumed as twice that of over 65s without cognitive impairment (Allan, Ballard, Rowan, & Kenny, 2009; Taylor, Lord, Delbaere, Mikolaizak, & Close, 2012), at a rate of 21.3 per 1,000. A ratio of 5:2 was assumed for driving collisions (Man-Son-Hing, Marshall, Molnar, & Wilson, 2007). Prevalence rates regarding causing accidental fires were not available so the most conservative assumption was made, i.e. that all recorded accidental fires for over 65s were caused by persons with dementia. As half of all accidental dwelling fires affect those over 65 (Department for Communities and Local Government, 2014), a rate of 22.7 out of 1,000 was assumed. Incidence of having a missing person's report filed was estimated at 5 in 1,000 (Bantry White & Montgomery, 2015).

### 2.1.9 | Visual aids for communicating dementia risks

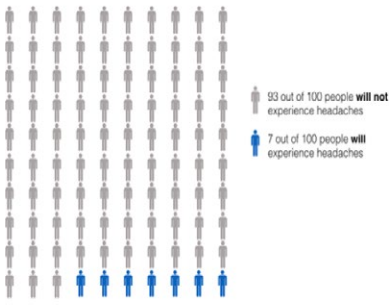
Participants selected from three formats for communicating about side effects of medication with a client (Zikmund-Fisher et al., 2014). The risk of headaches (x in 100) was displayed numerically accompanied by an icon array (100 figure icons presented in a 10 × 10 block with different colours for the number of people who did or did not experience the side effect); a bar chart; and in a simple frequency statement with no accompanying visual. Qualitative data were invited on the use of these visual aids (Figure 1).

### 2.1.10 | Challenges and practice issues

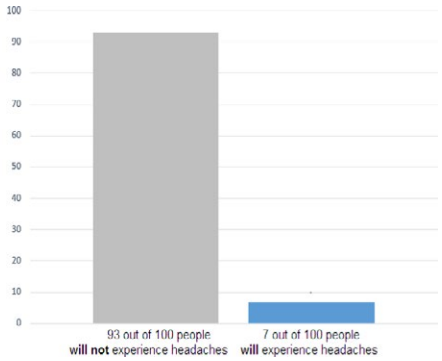
Respondents were asked to rate (scale 0–10) challenges in risk communication based on issues identified in the earlier studies. Qualitative data were gathered to explore useful heuristics or "rules of thumb" for addressing risk scenarios in dementia practice and ideas for enabling better risk communication.

Comments on the draft questionnaire were invited from the project Advisory Panel before piloting with two eldercare practitioners locally and four research staff at the Max Planck Institute of Human Development, Berlin. The Advisory Panel included the dementia services manager in each Health and Social Care Trust (who were either social workers or nurses) and 12 other individuals from five countries with expertise in dementia care, health communication, medicine, nursing, risk communication, social work, and speech and language therapy.

*Icon array*




*Bar chart*




*Verbal statement*

93 out of 100 people will not experience headaches. 7 out of 100 people will experience headaches.

**FIGURE 1** Icon array, bar chart and verbal statement used in the survey Images created by Iconarray.com. *Risk Science Center*, and *Center for Bioethics and Social Sciences in Medicine*, University of Michigan [Colour figure can be viewed at wileyonlinelibrary.com]

### 2.2 | Recruitment

The dementia services manager in each of the five publicly funded Health and Social Care Trusts in Northern Ireland invited all health and social care professionals (total 270 staff) in community dementia care to participate via email with accompanying electronic link to the survey. Data were collected from June to September 2016. Ethics approval was granted by the Health and Social Care Office of Research Ethics Committees, Northern Ireland.

### 2.3 | Analysis

Statistical analysis used SPSS Version 22. A minimum sample size of 85 participants was required to detect an effect size of 0.15 for multiple linear regression. Bivariate correlational analysis using Pearson's R was conducted on the 16 risk factors to correlate perceived frequency of risk and level of concern for that risk. The histograms indicated that the assumption of normality for correlational analysis was not met for 14 of the 16 risk factors. A bootstrapping method was therefore used with 95% confidence intervals. Correlational analyses were run for each of the theoretically selected predictors against the outcome variable for preliminary examination. Four predictors were tested in the models including experience (years in dementia practice and experience of relevant risk factors within their team); level of concern associated with the risk; and numeracy. All predictors were scale variables. Qualitative analysis involved a thematic analysis.

## 3 | RESULTS

Seventy complete and 55 partial responses (125 total) gave response rates of 26% (completed) and 46% (partial) (see Table 1). The appropriate denominator is used for analysis.

### 3.1 | Using numbers in practice

Average numeracy using BNT plus Schwartz items was low-moderate. Mean numeracy score ($n$ = 71) was 2.79 out of 7 ($SD$ 1.6; 95% CI [2.42, 3.16]). Scores for the four BNT items alone were low, 44% of respondents scored no correct answers on the BNT, 45% scored one correct, 6% (two correct), 4% (three correct) and 1% (four correct). Most respondents (86%) reported using numbers in practice (Table 2), primarily from assessment scores, likelihoods of side effects of medicines, reports, calculations for care packages and data from team databases.

### 3.2 | Numbers corresponding with verbal descriptors of risk

Participants' responses were variable on numeric estimates of verbal terms for risk likelihoods (of medication side effects). Few participants provided responses that were concordant with those used in the EU guidance. The median estimate for a side-effect risk described as "common" was 200 out of 1,000 (IQR 400), an estimate more aligned with an EU definition of "uncommon." The median estimate of "rare" was 20 out of 1,000 (IQR 69), more aligned with the EU definition of "common." No respondents provided a numeric estimate of "rare" that aligned with the EU description of this term, while only 15% of respondents estimated a value of "common" that fell within that EU range (Table 3).

### 3.3 | Verbal understanding of numerical probabilities

When asked to select a verbal descriptor that corresponded to a risk of 21 out of 1,000 from the five given descriptors (see above), most participants selected either rare (39%) or uncommon (45%) as the verbal statement they would use to communicate this value to a client. In the EU Guideline, this value would be within the "common" range (which 7% of respondents selected).

### 3.4 | Variability in understanding and use of verbal descriptors of risk

For the scenario in which respondents were asked to assess risk as high, medium or low; 25% of respondents selected low, 41% opted for medium and 34% chose high to describe the patient (client) risk level. To rate how likely it was that a client would experience a specific accident over 6 months, 55% choose "somewhat likely," while 13% selected "very likely," 12% likely, 15% somewhat likely, 4% unlikely and 1% very unlikely. When selecting a verbal statement to describe graphic information to colleagues ($n$ = 81), 49% of respondents selected a relative risk statement ("reduced by 50%" or "halved") to explain reduction in risk incidents. The absolute statement ("reduced from 12 incidents per week to 6 per week") was preferred by 28%, while remaining respondents selected a verbal descriptor: reduced (9%), moderately reduced (6%) or substantially reduced (7%).

### 3.5 | Visual risk communication tools

A visual form of communication was preferred by 81% (95% CI [71.5, 89.5]) respondents [$n$ = 82], with icon arrays (51%) being preferred to bar charts (29%). Explanations for preferred communication method generally related to perceived ease of understanding for the client. Icon arrays were noted as being clear, simple, providing a good illustration of proportions and being easier to relate to than graphs or words. Bar charts were favoured by some respondents, due to their familiarity. Respondents noted that bar charts aided comparisons between those who developed the risk outcome in that population compared to those who did not. Participants who favoured verbal statements felt that such statements were more direct while graphs could lead to confusion or information overload.

### 3.6 | Risks encountered in practice and levels of concern

Table 4 ranks the risk factors perceived as occurring most frequently (estimates out of 100, averaged across participants) and levels of

**TABLE 1** Demographics of sample completing the full questionnaire ($n$ = 70)

| | | |
|---|---|---|
| Gender | Female | 54 (77%) |
| | Male | 16 (23%) |
| Age | 21–30 years | 6 (9%) |
| | 31–40 years | 21 (30%) |
| | 41–50 years | 17 (24%) |
| | 51–60 years | 25 (36%) |
| | >61 years | 1 (1%) |
| Profession | Nursing | 32 (46%) |
| | Social Work | 13 (19%) |
| | Occupational Therapy | 11 (16%) |
| | Support Staff | 7 (10%) |
| | Medicine | 4 (6%) |
| | Speech and Language Therapy | 1 (1%) |
| | Psychology | 1 (1%) |
| | Other | 1 (1%) |
| Years in health and social care | Mean 17 years, newly qualified to 44 years in practice | |
| Years in dementia care | Mean 11 years, newly qualified to 35 years in practice | |
| Per cent of current role in dementia | Mean 84% | |
| Post-qualifying training | Specialist training in dementia (7), Approved Social Worker (5), Mental Health Nursing (3), Specialist Practitioner (Older People) (3), Adult Safeguarding (2), Initial Professional Development (2), NVQ Assessor (1), Research Methods (1), Practice Teaching (1). | |

concern associated with these (ranked out of 10). Based on $n$ = 89 sample, correlational analysis was powered (0.80) to detect a minimum effect size of 0.29. Findings provide a rudimentary estimate of the perceived frequency of these general risk factors in community dementia care teams, the three risks perceived as occurring most often being falls, depression and poor personal hygiene. Risks of most concern were abuse from others, falls and depression. Results demonstrate low to moderate positive correlations for 9 of the 16 risks presented (Figure 2). For risk of fire and abuse from others, levels of concern were high despite perceived frequency being low.

## 3.7 | Accuracy in estimations of severe risk outcomes

Professionals overestimated how often risks with severe outcomes occurred (comparing median estimates to recorded data, Table 5). Median estimates relating to going missing or having a serious fall were 10 times greater than the conservatively estimated reality. Responses were variable with wide interquartile ranges, in particular regarding serious falls.

Responses were classified as "accurate" if they fell within the range of half to double our calculated estimate as a notional "reasonable" professional knowledge base. Percentage of accurate responses for each severe risk outcome category ranged from 10.8% (serious fall) to 29.8% (car accident). Most practitioners (76%) made either none or one accurate estimate across all four scenarios, while no respondents were accurate in their estimates across all four. The number of accurate estimates per respondent was: 0 (46%); 1 (30%); 2 (20%); 3 (4%); and 4 (0%) of the total 83 accurate estimates.

## 3.8 | Predictors of accuracy

Diagnostics for multiple linear regression confirmed that assumptions of linearity, normality of residuals and homoscedasticity were violated for all models. A logistic regression model was used where accuracy was classified as a binary variable (accurate/inaccurate). However, the model was not adequately powered (0.80) to detect small effect sizes (Chen, Cohen, & Chen, 2010; Hsieh, 1989). None of the logistic models could accommodate all four of the predictor variables when applying the "one in ten rule," i.e. for every 10 respondents in the smallest category, one predictor variable could be added to that model (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996; Stoltzfus, 2011).

Correlational analysis with bootstrapping was used to explore relationships between accuracy (as a continuum from underestimations to overestimations) and the four theoretically driven variables (Table 6). Numeracy and experience were not correlated with accuracy of estimation. Two variables (experience of the general risk factor

**TABLE 2** Use of numeric data in practice ($n$ = 125)

| Numeric data source | |
|---|---|
| Mini Mental State Exam | 69% |
| Abbey Pain Scale | 42% |
| Addenbrookes Cognitive Assessment | 42% |
| Reports on how often client incidents have occurred | 42% |
| Braden Pain Scale | 42% |
| Geriatric Depression Scale | 36% |
| Malnutrition Universal Screening Tool | 28% |
| Hospital Anxiety and Depression Scale | 14% |
| Likelihood of side effects of medications or treatment | 13% |
| Montreal Cognitive Assessment | 12% |
| Other | |
| Other assessment tools | 10% |
| 4AT (cognitive impairment and delirium) | |
| Abbreviated Mental Test (AMT) | |
| Calculating care packages | |
| Challenging Behaviour Scale (Moniz-Cook, Woods, Gardiner, Silver, & Agar, 2001) | |
| Clifton Assessment Procedures for the Elderly (CAPE) | |
| Cohen-Mansfield Agitation Inventory (CMAI) | |
| Cornell Depression Scale (CDS) | |
| EASY-Care (physical, mental, social and environmental assessment) | |
| Falls risk checklist | |
| Neuropsychiatric Inventory (NI) | |
| Pool Activity Level (PAL) assessment | |
| SAD suicide assessment | |
| St Andrews Sexual Behaviour assessment scale (SASBA) | |
| Data from team database, e.g. length of waiting times or average length of episode | |
| Do not use numeric information in work | 14% |

and concern) were significantly correlated at $p < .05$ with overestimation of risk, but were not consistently associated with significant levels of overestimation across all four severe risk outcome situations. Increased experience of the general risk factor within the team was significantly associated with moderate increased overestimation of the risk likelihood for two risk factors (experience of falls from minor to severe and experience of people with dementia "wandering"). Increased concern relating to the general risk factor was significantly associated with low to moderate increased overestimation of the risk likelihood for three of the risk factors (experience of falls, driving accidents and fire). Confidence intervals are wide ranging from small effects to moderate effects for those associations that were significant at $p < .05$.

### 3.9 | Challenges for risk communication in practice

Table 7 ranks challenges relating to communicating risk from 0 (not challenging at all) to 10 (extremely challenging) in descending order. Conflicting ideas on clients' best interests was rated as the greatest challenge, closely followed by the person with dementia lacking insight into the risk, while fear of complaint was regarded as least challenging of the issues presented.

### 3.10 | General principles for communicating and managing risks

Respondents outlined general principles they would apply to a case-based "risk" scenario:

- Gathering more information to place the risk behaviour in context;
- Weighing the "risk" against potential benefits;
- Monitoring the situation;
- Further assessment; and
- Considering potential supports and strategies to reduce risk.

Suggestions to improve risk communication included: further training (including for staff who do not work within dementia services); availability of quality resources including information booklets offering practical guidance; access to a sound research base; availability of data on likelihoods of risks; and visual aids to explain risks.

## 4 | DISCUSSION

The complete-questionnaire response rate was typical of busy professionals, but the main limitation of the study is that it was slightly below the desired number required for the power calculation for some questions. From piloting, the whole questionnaire was estimated to take about 15 min to complete. The large number of partial completions is noteworthy. Our concern was that the numeracy question would be found daunting so this was put later in the questionnaire, although in fact participants dropped out incrementally from an early stage. It is speculated that respondents were prioritising their normal work, despite encouragement from managers for the study. Although there was a reasonable response from nurses and social workers (the most numerous professionals), there was a particularly low response from medical doctors.

As community care increasingly involves considering possible harm, professionals need to develop risk communication knowledge and skills as part of their repertoire in order to manage diverse risks (Thwaites et al., 2017) in accordance with developing national and organisational policies in line with consumer perspectives (Department of Health, 2007, 2010). The study of risk communication is bridging the gap between approaches to assessing and managing risk (Bantry White & Montgomery, 2016) and understandings of professional judgement and decision-making (Keller, Siegrist, & Gutscher, 2006; Taylor, 2017b). However, approaches to risk communication need to broaden beyond the better-established research area of numeric communication about the side effects of medicines (Bahri, 2010) to encompass the diversity of risks, communication modes and contexts

encountered in health and social care. This includes variation across client, family and different professional understandings of "risk" and "risk management."

Numeracy scores were in the low-moderate range, consistent with studies demonstrating that even highly educated samples have difficulty understanding numeric information (Garcia-Retamero, Cokely, Wicki, & Joeris, 2016). This study did not find a significant association between numeracy and accurate perceptions of risk likelihoods in practice-based scenarios, although it did highlight the need to develop risk literacy among dementia care practitioners. Even where professionals are well-informed, the perception of the likelihood of "dread risks" is dependent of course on the quality of routinely gathered information (on such as house fires, etc.). It may be that numeracy varied across professional disciplines, although detail on this was beyond the scope of this study.

Practitioners saw potential in using visual aids to communicate risk likelihoods, based on such as the ideas tested here (Garcia-Retamero & Cokely, 2017; McDowell, 2016). Studies are required on types of icons (Arcia et al., 2016), adaptation to age (Finucane, 2008), and for patients and clients with impaired cognitive ability.

Professionals generally overestimated the frequency of occurrence of serious harmful events in the population. There is diverse speculation on cognitive mechanisms underpinning judgements of risk frequencies (Harris & Corner, 2011; Hertwig, Pachur, & Kurzenhäuser, 2005), in particular how these relate to decision processes (Meder, Mayrhofer, & Waldmann, 2014) and professional role (Taylor, 2017a). People might become blasé when they experience (adverse) events frequently (Hertwig & Erev, 2009), although the present findings do not confirm that effect. Knowledgeable professionals should be able to distinguish between the "seriousness" of the possible harm and its "likelihood" to decide on their "concerns" (Stevenson & Taylor, in press a). Further studies with larger sample sizes and increased power are needed to identify predictors of accuracy and related knowledge to inform best practice.

There was variation in both verbal descriptors selected to describe numeric values and the numeric interpretation of words for probability of harm, reflecting the high variability in the literature (Budescu, Por, & Broomell, 2011). As words, rather than numbers, are widely used (Stevenson & Taylor, in press a), this is a particular

**TABLE 3** Categorisation by EU categories of respondents' numeric understanding of the terms "rare" and "common" in relation to side effects of medicines ($n$ = 83)

| EU verbal descriptor | Numeric understanding of "Rare" in the range | Numeric understanding of "Common" in the range |
|---|---|---|
| Very rare (<1 in 10,000) | 3.6% | 1.2% |
| Rare (≥1 in 10,000 to <1 in 1,000) | 0% | 0% |
| Uncommon (≥1 in 1,000 to <1 in 100) | 21.7% | 2.4% |
| Common (≥1 in 100 to <1 in 10) | 51.8% | 14.5% |
| Very common (≥1 in 10) | 22.9% | 81.9% |

**TABLE 4** Perceived frequency of risk factors among dementia team clients and levels of concern

| | Frequency ($n$ = 99) | | Concern ($n$ = 89) | | |
|---|---|---|---|---|---|
| Risk | Mean | Median | Mean | Median | Correlation with bootstrapping [95% CI] |
| Falls | 53.6 (*SD* 24.2) | 50 | 6.7 (*SD* 2.7) | 7 | $r$ = .45, $p$ < .001* [0.26, 0.62] |
| Depression | 43.8 (*SD* 24.7) | 48 | 6.5 (*SD* 2.5) | 7 | $r$ = .41, $p$ < .001* [0.23, 0.57] |
| Poor personal hygiene | 43.3 (*SD* 25.1) | 41 | 4.4 (*SD* 2.6) | 4 | $r$ = .26, $p$ = .013* [0.03, 0.50] |
| Medications mismanagement | 40.5 (*SD* 26.7) | 35 | 6.4 (*SD* 3.2) | 7 | $r$ = .27, $p$ = .011* [0.06, 0.44] |
| Leaving home unsupervised | 31.4 (*SD* 24.8) | 25 | 6.0 (*SD* 3.3) | 6 | $r$ = −.03, $p$ = .753 [−0.21, 0.25] |
| Financial mismanagement | 28.3 (*SD* 27.2) | 20 | 5.6 (*SD* 3.2) | 6 | $r$ = .35, $p$ = .001* [0.17, 0.51] |
| Malnutrition | 26.4 (*SD* 24.5) | 17 | 5.9 (*SD* 3.3) | 6 | $r$ = .21, $p$ = .044* [−0.004, 0.10] |
| Swallowing difficulties | 24.1 (*SD* 24.9) | 13 | 6.1 (*SD* 3.3) | 7 | $r$ = .18, $p$ = .09 [0.002, 0.35] |
| Abuse from others | 20.2 (*SD* 25.1) | 10 | 7.0 (*SD* 3.0) | 8 | $r$ = .09, $p$ = .394 [−0.07, 0.24] |
| Risks to others | 20.0 (*SD* 21.5) | 12 | 5.4 (*SD* 3.3) | 6 | $r$ = .22, $p$ = .041* [0.03, 0.41] |
| Accident from using appliance | 19.6 (*SD* 22.9) | 10 | 5.3 (*SD* 3.4) | 6 | $r$ = .26, $p$ = .015* [0.08, 0.45] |
| Refusing equipment | 17.9 (*SD* 20.5) | 10 | 4.3 (*SD* 2.9) | 5 | $r$ = .26, $p$ = .014* [0.06, 0.44] |
| Fire | 11.7 (*SD* 19.8) | 4 | 6.2 (*SD* 3.9) | 8 | $r$ = .05, $p$ = .627 [−0.12, 0.22] |
| Driving accident | 11.5 (*SD* 18.6) | 5 | 5.2 (*SD* 3.8) | 5 | $r$ = .12, $p$ = .276 [−0.01, 0.25] |
| Alcohol abuse | 11.3 (*SD* 11.4) | 10 | 3.9 (*SD* 2.8) | 3 | $r$ = .18, $p$ = .087 [0.02, 0.34] |
| Bathing accident | 9.5 (*SD* 15.1) | 3 | 4.0 (*SD* 3.3) | 4 | $r$ = .16, $p$ = .133 [0.01, 0.31] |

*Significant at .05 level (two-tailed).

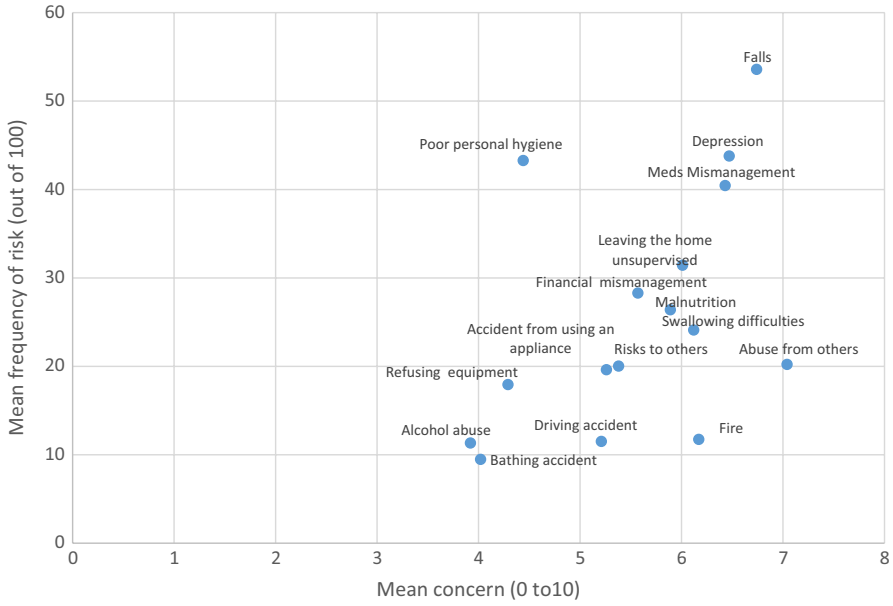



**FIGURE 2** Relationships between risk frequency and risk concern [Colour figure can be viewed at wileyonlinelibrary.com]

**TABLE 5** Perception of likelihood for dread risks compared to estimated actual data ($n$ = 83)

| Severe risk outcome (over the next 12 months) | Actual[a] (out of 1,000) | Median estimate (out of 1,000) | % Accurate (−50% to +100% of actual) |
|---|---|---|---|
| Be involved in a car accident | 27 | 50 (IQR 133) | 29.8% |
| Cause a fire in the home | 22.7 | 50 (IQR 90) | 19.3% |
| Have a missing person's report filed | 5 | 50 (IQR 190) | 21.7% |
| Have a serious fall resulting in hospitalisation | 21.3 | 200 (IQR 440) | 10.8% |

[a]Based on recorded data.

**TABLE 6** Correlation of accuracy with numeracy, experience and concern

| | Numeracy ($n$ = 71)[a] | Experience (years in dementia practice) ($n$ = 70)[a] | Experience (of general risk factor) ($n$ = 83)[b] | Concern ($n$ = 83)[b] |
|---|---|---|---|---|
| Serious fall | $r$ = −.029, $p$ = .811 95% CI [−0.235, 0.175] | $r$ = −.082, $p$ = .5 95% CI [−0.295, 0.140] | $r$ = .397[a], $p$ < .001 95% CI [0.214, 0.565] | $r$ = .232[a], $p$ = .035 95% CI [0.012, 0.438] |
| Cause fire | $r$ = −.071, $p$ = .556 95% CI [−0.304, 0.173] | $r$ = .102, $p$ = .399 95% CI [−0.069, 0.281] | $r$ = .089, $p$ = .425 95% CI [−0.057, 0.290] | $r$ = .258[a], $p$ = .019 95% CI [0.078, 0.406] |
| Missing persons report | $r$ = −.059, $p$ = .624 95% CI [−0.267, 0.145] | $r$ = −.016, $p$ = .895 95% CI [−0.230, 0.199] | $r$ = .300[a], $p$ = .006 95% CI [0.107, 0.491] | $r$ = .134, $p$ = .226 95% CI [−0.079, 0.317] |
| Car accident | $r$ = .014, $p$ = .911 95% CI [−0.237, 0.189] | $r$ = .047, $p$ = .698 95% CI [−0.099, 0.268] | $r$ = .096, $p$ = .385 95% CI [−0.021, 0.286] | $r$ = .273[a], $p$ = .012 95% CI [0.077, 0.444] |

[a]Powered to detect minimum effect size of 0.33.
[b]Powered to detect minimum effect size of 0.30.

area for research. Building on existing studies (Mosteller & Youtz, 1990), now is the time for coherent work on developing standardised, evidence-based lexicons (where verbal terms used to communicate uncertainties are attached to specific numeric ranges) to improve risk communication (Ho, Budescu, Dhami, & Mandel, 2015). While guidance on the relationship between numbers and words for frequency is available for communicating side effects of medications, practitioner interpretations did not generally align with even a widely established correspondence. The scaling of words against numbers for risks may be context-specific (McDowell, Rebitschek, Gigerenzer, & Wegwarth, 2016; Taylor, 2017b). It is noteworthy that the EU requires the use of numbers as well as words in medicine labelling. It may be that verbal descriptors make most sense within a group of people who have agreed on the numeric correspondence of terms. Research is needed focusing on personal and contextual factors (Büchter et al., 2014) that influence the semantic logic. The

**TABLE 7** Perceived challenges in practice ($n$ = 71)

| | |
|---|---|
| Conflicting ideas on client's best interests | 6.9 (*SD* 2.2) 95% CI [6.4, 7.4] |
| Person with dementia lacking insight into the risk | 6.3 (*SD* 2.6) 95% CI [5.7, 6.9] |
| Unrealistic expectations of services | 6.0 (*SD* 2.8) 95% CI [5.3, 6.6] |
| Risk of damage to professional/client relationship | 4.8 (*SD* 2.8) 95% CI [4.1, 5.5] |
| Lack of data on likelihoods | 3.4 (*SD* 2.7) 95% CI [2.8, 4.1] |
| Fear of complaint | 2.6 (*SD* 2.2) 95% CI [2.1, 3.1] |

development of guidance needs to involve clients, families and professionals (Taylor, 2017a) as well as taking account of diverse needs and expectations in relation to risk communication.

## 5 | CONCLUSIONS

Risk communication is at the conflux of interest between educating and empowering people regarding their own health and care, and in equipping health and social care professionals to reconceptualise their roles in a "world of risk management." These micro-skills represent a practice issue essential to community care policy. Health and social care professionals need to develop clarity of communication about risk and benefits, and thereby improve decision processes. This requires a knowledge base readily available in the workplace, as well as supportive mechanisms to enable connection to practice. Professional and employing bodies, as well as individual professionals, need to rise to the challenges—and possibilities—presented by the developing world of *risk literacy* in order to most effectively support patients, clients and families in making informed and reasoned decisions about their care in the face of risk and uncertainty.

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