

2012 UPDATED CHAPTER E: USING PERSONAL STORIES

SECTION 1: AUTHORS/AFFILIATIONS

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SECTION 2: CHAPTER SUMMARY

What is this quality dimension?

Personal stories are narratives that provide illustrative examples of others' experiences relevant to the decision. Within patient decision aids, personal stories provide one person's interpretation of an aspect of the decision experience for consideration by the decision maker. These stories can be presented as text, audio and video clips, and face-to-face encounters. Personal stories can be delivered by the person whose story it is or an actor. Personal stories may include narratives from the 1st-person (e.g., patients' or carers' accounts of their own experience) and the 3rd-person (e.g., professionals' or carers' account of the other's experience) perspectives, and representations of the conversations between the patient and another person (e.g., patient plus professionals and/or carer).

What is the theoretical rationale for including this quality dimension?

There is no single theoretical approach explaining how and/or why personal stories influence the way individuals process, interpret, and represent information in a way that supports people's informed decision making. Within health care, personal stories are used: in research as a method to investigate meanings about health and illness; as an established resource in the education of professionals and patients; and as part of the therapeutic encounter. Patients find others' stories of the illness experience important to their healthcare choices. Personal stories are also seen as active ingredients within interventions designed to change people's behaviour

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rather than facilitate informed decision making. Personal stories have the potential to either hinder or facilitate patients' informed decision making. What is unclear is how to incorporate personal stories, and/or the information contained within narratives, in a way that enhances the effectiveness of decision aid to facilitate patients' decision making.

What is the evidence to support including or excluding this quality dimension?

There is insufficient evidence examining whether or not personal stories contribute to the effectiveness of patient decision aid interventions. Of the 10 studies since 2005 that investigated the added value of personal stories and their impact on informed decision making, all found that personal stories affected the judgements and choices of participants differentially from presenting facts alone. There was variability in the way personal stories were sourced, constructed, delivered, integrated within the intervention, and evaluated. The study purpose, and therefore the function of the personal story, varied in terms of investigating either biases in decision making, health behaviour change, or participant engagement with information. As a result, the synthesis was not able to identify the active ingredients of the personal story that may enhance, or limit, the effectiveness of patient decision aid interventions.

However, there were some similarities across the experimental and real-world studies, suggesting that people use both personal story and factual information when making healthcare decisions, and that there is an interplay between the processing of personal story and factual information with subsequent attention to information, evaluations, and decisions. It was unclear how this interplay could be maximised to ensure patients' healthcare decision making was supported rather than biased. There was little evidence that personal stories were associated with enhancing health literacy over and above the other component parts of a decision aid intervention.

SECTION 3: DEFINITION (CONCEPTUAL/OPERATIONAL) OF THIS QUALITY DIMENSION

a) Original Definition

The 2005 edition of this chapter described personal stories as “examples of others’ experiences with decision making”. Implicit in the 2005 definition was the assumption that personal stories were synonymous with patient narratives or testimonials. Most decision aids that included a personal story provided at least one example of a patient narrative or testimonial about his/her decision making and consequences of the choice made; experimental studies tested the impact of receiving information as a patient testimonial compared with standard (statistical) information on hypothetical treatment choices (e.g., Ubel et al., 2001).

b) Updated Definition

This edition of the chapter defines personal stories more broadly as “narratives that provide illustrative examples of others’ experiences relevant to the decision”. This description recognises the range of ‘others’ who have narratives of relevance to a patient’s decision (e.g., carers, family, and professionals). Narratives provide a coherent causal account of an experience that has occurred or that is expected to occur. Narratives provide a structure or plot to shape a person’s interpretation of an event or experience (Murray, 2003). The story provides the meaning, time-line, and context of an event from the narrator’s perspective,

causally linking their knowledge, beliefs, experiences, actions, and emotions with social and ethical mores of relevance to that person (Greenhalgh and Hurwitz, 1999; Hyden, 1997; Bury, 2001).

Within patient decision aids, personal stories provide one person's interpretation of an aspect of the decision experience for consideration by the decision maker. These stories can be presented as text in leaflets (with and without photos and/or images), audio and video clips (via DVDs and/or internet providers), and face-to-face encounters (individually or in groups). Personal stories can be delivered by the person whose story it is or by an actor. Personal stories may include narratives from the 1st-person (e.g., the patients' or carers' accounts of their own experience) and the 3rd-person (e.g., the professionals' or carers' account of the other's experience) perspectives, and representations of discussions between the patient and another person (e.g., patient plus professionals and/or carer). The following describes the range of resources we considered:

- Testimonials of patients (or actors) talking about their experiences relevant to the decision.
- Scripted narratives of patients (or actors) talking about their experiences relevant to the decision.
- Narratives by health professionals (or actors) describing their patients' decision making experiences.
- Documentaries (real or enacted) illustrating the interaction between patients with professionals and others (e.g., family, carers) when making decisions about healthcare options.
- Conversations (real or enacted) illustrating the interaction between patients with other parties (e.g., health professionals, family or carers) when making decisions about healthcare options.

c) **Emerging Issues/Research Areas in Definition**

The emerging issue is the usefulness of this definition in allowing others to classify personal stories as a discrete component of patient decision aids over and above the other components of patient decision aids (e.g., information about the decision options, attributes and consequences; information content and accessibility; value and risk clarification; mode of delivery).

SECTION 4: THEORETICAL RATIONALE FOR INCLUDING THIS QUALITY DIMENSION

a) **Original Theoretical Rationale**

In 2005, the rationale provided for including patient stories within decision aids was informed by findings that patients like receiving information as a story, find stories more memorable than information about facts and figures, and find others' experience of treatment decision making and illness useful. Patient stories were identified as having four functions (which will be revisited here in a later section):

- To provide factual information to help patients understand the options and their outcomes

- To demonstrate how patients value decisions differently
- To share a range of opinions
- To exemplify the steps others have used to make a decision

No theoretical framework was explored explicitly within the previous version of the chapter to explain why personal stories should be included within patient decision aids. Narratives were perceived as providing essential emotional and social information not usually found within routine resources that provide meaning and perspective to a patient's predicament (Greenhalgh, 1999). For health professionals and patients, personal stories, illness scripts, and narratives were deemed to be a valued resource to enable understanding of a patient's experience of an illness and the impact of an illness on the patient's life and wellbeing, and to provide insights into coping, adjusting, and living with its consequences (Hyden, 1997; Bury, 2001). It was suggested that personal stories were beneficial to patients' healthcare decision making because a) information within narratives is easier to process, and b) narratives provide another person's reasoning, and so enable patients to learn how to make decisions, i.e., enhancing their "decision literacy". The authors noted some concerns about personal stories and possible limitations in enhancing informed patient decisions, specifically:

- One story cannot represent all the possible consequences and may over-ride consideration of more representative facts and figures.
- Which stories are chosen could alter the 'balance of information' presented within the decision aid and bias patients' interpretation of the other information in the decision aid.
- Stories in which the patient identifies the choice they made may demonstrate a biased thinking process due to post-choice justifications and cognitive dissonance.
- Those who have not survived cannot tell their story and the survivors may misrepresent aspects of the experience.
- Some stories may have been selected by non-impartial investigators; for example, providers or patients wanting to endorse one option over and above another (e.g., an unlicensed treatment).
- There is often inequity between the rigor undertaken to choose and develop decision information with that to select the section of the patient narrative for inclusion in the decision aid.

b) Updated Theoretical Rationale

Currently, there is no single theoretical approach explaining how and/or why personal stories influence the way individuals process, interpret, and represent information in a way that supports people's informed decision making. Hinyard and Kreuter (2007) summarise several theories to understanding the mechanisms within narratives that motivate and support health behaviour change that are of relevance to this chapter (see section below). Findings reinforce the issues raised above, and suggest a) others' stories of their illness experience are important to patients' healthcare choices (Morton et al., 2010; Entwistle et al., 2011), and b) information presented within personal stories affects individuals' judgments and choices differentially from presenting factual information (Winterbottom et al., 2008).

Without a clearer theoretical framework to guide the research, it is unclear whether or not this influential way of presenting information enhances the effectiveness of patient decision aids. The absence of a theoretical framework for personal-stories research is, in part, attributable to stories or narratives being used as a *method* by which to investigate meaning (Greenhalgh, 1999), providing explanations of identity and society, specifically in the context of health and

illness (Murray, 2007). Partly it may have arisen because patient narratives are an established resource in the education of professionals and patients, and the therapeutic encounter (Greenhalgh, 1999). However, it is feasible that providing a personal story about someone else's treatment experience encourages patients to evaluate another's decision making rather than reason about the facts in accordance with their own values—that is, may discourage patients from making informed decisions (Gavaruzzi et al., 2011).

c) **Emerging Issues/Research Areas in Rationale**

Two pressing theoretical issues for the use of personal stories within patient decision aids are to:

- *Understand the dimensions* that constitute personal stories. We need to recognise that personal stories are themselves complex interventions, providing the decision maker with different types of information from that presented in factual information. The structure, content, and function of personal stories vary, but few authors describe these dimensions within their dissemination. We need to be able to identify the active ingredients within personal stories and assess their role in facilitating or biasing patients' decision making. Shaffer and Zikmund-Fisher (2012) have begun to unpack these dimensions with a taxonomy to encourage decision aid developers to think of the purpose of their intervention (e.g., inform, engage, model behaviour, persuade, comfort) and the narrative's content (e.g., process of decision making; decision experience; decision outcome).
- *Identify the mechanisms* by which personal stories influence individuals' judgments and choices. Decision scientists suggest we have two broad systems for processing information when making decisions: an experiential-automatic process (system 1) that is quick, effortless, and does not require deliberation before action (e.g., relying on an heuristic or rule of thumb such as trust in another's judgments); and an analytic-deliberative process (system 2) that is effortful, cognitively demanding, and requires active reasoning before action (e.g., weighing up the advantages and disadvantages of all options) (see Kahneman & Frederick, 2002; Stanovich, 1999; Epstein et al., 1996; Slovic et al., 2005). Particular aspects of the type, structure, and content of personal stories have been identified as encouraging automatic processing of the decision information—for example: the credibility of the narrator (Chaiken and Maheswaran, 1994); the affective and/or value terms used within the story (Habermass et al., 2010; Ito et al., 1998; Loewenstein, 2005; Dillard, 2010); the social references a narrator provides implicitly when telling a story (Sherif and Hovland, 1961; Festinger, 1954; Bandura, 1989); and the temporal and causal framework provided implicitly by having to link together events in order to tell a story (McClelland, 1988; Mandler & Johnson, 1977; Schank and Berman, 2002). Equally, particular aspects have been identified as encouraging deliberative processing—for example: increasing motivation to attend to the information (Petty and Cacioppo, 1986); making the information more salient and memorable (Price and Czilli, 1996; Sanfrey and Hastie, Satterfield, 2001); and modelling the process of decision making through depiction of interactions with others (Jibaja-Weiss and Volk, 2007).

Personal stories have the potential to either hinder or facilitate patients' informed decision making (see **Table 1**). What is unclear is how to incorporate personal stories, and/or the information contained within narratives, in a way that enhances the effectiveness of decision aid to facilitate patients' decision making.

Table 1: Explanations For The Biasing or Facilitating Role of Information Within Personal Stories

Use Of Personal Stories That May Hinder Informed Decision Making	Use Of Personal Stories That May Facilitate Informed Decision Making
Selected facts used by the other person to justify their choice post hoc.	Increase decision literacy by explaining how others make sense of the facts to reach a decision.
Processing another person's rationale, values, experiences and choice to make a choice.	Increase patients' awareness of how others' stories may be different from their own experience (i.e., de-bias impact of others' stories).
Prioritises information already linked within the personal story making it more easily processed and remembered than other information.	Provide information to help people have realistic expectations about some of the decision consequences (e.g., I had x problem, dealt with in this way).
Patients make choice based on their reaction to the person delivering the story not the information content (e.g., that person is/ is not like me).	Provides 'appropriate' social reference information (e.g., other patients in this clinic/with this condition).
Rationale provided in other's story is based on their reasons for choosing option x and rejecting options y and z rather than evaluating pros and cons of all options i.e. early closing down of options.	Provides an illustration that a) trade-offs need to be made on the patient's evaluations, and b) how to make a trade-off (e.g., treatment x is riskier but quicker with permanent impact/ option y is shorter, less risky with unclear impact).
Introduces more value-laden and emotional terms because using 'natural' language.	Provides a way of acknowledging emotional aspects of decision making (e.g., it was really hard to communicate my decision with my family).

SECTION 5:**EVIDENCE BASE UNDERLYING THIS QUALITY DIMENSION****a) Original Evidence Base**

In 2005, there was limited and conflicting evidence regarding the usefulness of personal stories within patient decision aid interventions. Although 14/29 patient decision aids included patient narratives, patient stories were integrated within the decision aid and their independent contribution to enabling informed decision making could not be assessed (O'Connor Cochrane Collaboration review, 2003). Subsequently, in 2008, a review identified 17 studies which examined the influence of narratives on people's judgments and choices compared with the presentation of factual information, 7 carried out in real-world settings (Winterbottom, 2008). A third of the studies found that narratives affected the choices and judgments of participants, with 1st-person narratives being more than twice as likely to influence people's choices than 3rd-person narratives.

b) Updated Evidence Base

Updating Process

For this 2011 version of the chapter, we carried out a scoping review to identify studies evaluating a personal story component of a decision aid on people's healthcare decision making. The search strategy included: *decision making terms* (decision making, decision support, decision aid, decision theory, choice, preference) + *personal story terms* (narratives, patient stories, anecdotal evidence, testimonials, exemplars).

Two electronic databases were searched, Medline (2005 to January 2011) and PsycINFO (2005 to January 2011); 734 articles were identified in the search. Additionally, the reference lists of relevant reviews were searched (e.g., Stacey et al., 2011; Feldman-Stewart et al., 2006; Winterbottom et al., 2008; Hinyard and Kreuter, 2007; Clement et al., 2009; Bekker, 2010) and key authors in the field were contacted and/or an author search carried out using Google Scholar.

The inclusion criteria were developed to identify those articles that evaluated a personal story element over and above a decision aid on people's healthcare decisions; articles evaluating the role of personal stories compared with standard information provision were excluded from the review (see **Table 2**).

Table 2: Inclusion And Exclusion Criteria For The Scoping Review

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> ● Studies evaluating a personal story component of a decision aid on people's healthcare decision making ● Individuals making real or hypothetical decisions ● Personal stories in the first or third person ● Experimental and/or RCT designs; before and after studies and/or cohort studies ● An adult population ● Published in English 	<ul style="list-style-type: none"> ● Studies assessing message framing only ● Studies assessing video or verbal (narrative) formats of information delivery only ● Proxy decision making, i.e. decision making by an individual for another ● Non-experimental or single-case designs. ● Discussion and/or review papers

Noteworthy Exclusions

- Wise et al. (2008) was excluded because their primary outcome was women's *preferences for participation* and the study design was *non-experimental*. The study explored the impact of different types of information, narrative and/or factual (didactic), within a web-based resource about breast cancer (CHESS) on women's preferences for healthcare participation. Findings indicated both sources of information were associated with perceived healthcare participation, regardless of education level. However, the strength of the association was higher for African American women. The authors hypothesised that narrative information enabled women to process, store, and retrieve the factual (didactic) information more effectively.

- Studies investigating the *different ways of presenting factual information on personal perceptions of risk* and intended choices/behaviours were excluded from this chapter (see Chapter C: Presenting Probabilities). Studies of risk presentation and perception are theoretically important to this chapter, as they provide explanations for why presenting information as narratives may be disproportionately more persuasive than the figures (statistical information), and in which contexts (for example, de Wit et al., 2011; Betsch et al., 2011). Findings indicate: a) people make choices based on integrating both statistical and narrative information; b) narrative information influences people's choices directly and in-directly via cognitions such as perceptions of personal risk; and c) the persuasive effect of narrative, or statistical, information varies with reference to the initial perspective of the decision maker (Betsch et al., 2011; de Wit et al., 2008). Some of the possible explanations for the persuasiveness of narrative information include:

- *memory* (supplementary narratives within health information interrupt people's processing, and recall, of the factual information (Betsch et al., 2011));

- *evaluation* (narrative information is less threatening than statistical information and so circumvents the initiation of defensive responses associated with negative affect (de Wit et al., 2008), or is integrated by automatic processes and so is more difficult to discount analytically, or is given more weight because of the narrative's characteristics (e.g., emotion) (de Wit et al., 2008; Betsch et al., 2011); and

- *dual-process controller* (if narrative and statistical information is processed differently, then there is likely to be an interplay between the judgments made from evaluating statistical or narrative information first, and the person's motivation to attend to and assimilate further information (Betsch et al., 2011)).

Results of Scoping Review

We identified 10 published articles that provide some evidence about the contribution of a personal story component within a patient decision aid to people's healthcare choices (see **Tables 3 & 4**). There is still a paucity of research exploring the added value of personal stories within patient decision aids and its impact on informed decision making. Of the 10 identified articles, 3 evaluated their interventions with patients making a healthcare choice (Volk et al., 2008; Jijaba-Weiss et al., 2011; Kreuter et al., 2010); the rest elicited preferences (Volandes et al., 2009; 2010; 2011; El-Jawahri et al., 2010) and/or hypothetical choices (Fagerlin et al., 2005; Dillard et al., 2010; Winterbottom et al., 2011).

The health contexts were: screening for prostate (Volk et al., 2008), breast (Kreuter et al., 2010) and colorectal cancer (Dillard et al., 2010); treatment decisions between angioplasty/bypass surgery (Fagerlin et al., 2005), mastectomy/breast conserving surgery (Jijaba-Weiss et al., 2011), and peritoneal dialysis/ haemodialysis (Winterbottom et al., 2011); and end of life level of care in cancer (El-Jawahri et al., 2010) and dementia (Volandes et al., 2009; 2009b; 2011). Interventions were delivered directly via access to web links (Fagerlin et al., 2005; Dillard et al., 2010; Winterbottom et al., 2011) or face-to-face with computer support (Volandes et al., 2009; 2010; 2011; El-Jawahri et al., 2010; Volk et al., 2008, Volk et al., 2008).

The research falls into three groups.

- *The first set of studies* drew on the decision sciences to test whether component parts of decision aids and personal stories bias and facilitate people's informed decision making about healthcare decisions. Fagerlin et al. (2005) reports two related studies investigating

the single and combined impact of patient anecdotes and statistical information within information about angina and treatment options. Winterbottom et al. (2011) report two related studies investigating the single and combined impact of a patient story, a decision-attribute table, and balanced information about chronic kidney disease and dialysis options. In both studies, the patient narratives influenced the choices that participants made in keeping with the patients' stories. Clearly presented statistical information countered the bias introduced by the patient anecdotes in the angina context. However, structuring information within a decision-attribute table did not counter the effect of the patient story.

- *The second set of studies* drew on the behavioural sciences and persuasion literature to investigate targeting or tailoring information within personal stories on the barriers towards having screening (Hindyard and Kreuter, 2007). Kreuter et al. (2010) developed two videos, one using clips from videos of women's views and experiences towards mammography screening ("living proof"), the other a narrated version of the information contained with the transcript of living proof ("facts for life"). Dillard et al. (2010) developed a web-based decision aid that provided patient messages tailored to the answers participants gave in the pre-intervention questionnaire, compared with the decision aid without the messages. Across both studies, in the personal stories groups there were initial increases in cancer fears and decreases in the perception of barriers to screening, and some trends towards increases in knowledge or recall of facts and interest in screening.

- *The third set of studies* drew on educational and/or communication theory to develop interventions to increase engagement with patient decision aids, particularly in groups with variable education levels (sometimes known as *edutainment interventions*) (Vaughan and Rogers, 2000; Jibaja-Weiss and Volk, 2007). All of these interventions had a comparison group that were provided with equivalent information without personal stories. However, the intervention with the personal story usually contained other component parts (e.g., information delivered by a different medium, provision of a resource to aid memory, a clearer structure, or interactive or tailoring exercises) that may explain the findings. Volandes (2009, 2009b, 2011) and El-Jawahri (2011) had two groups that received information about the disease and care-plan options verbally; the intervention group then watched an additional video with clips of procedures and/or personal stories. Volk et al. (2008) compared an audio-booklet with an entertainment-based intervention containing interactive learning modules and stories presented as tele-novellas. Jibaja-Weiss et al. (2010) compared routine information about the facts and figures of the disease and choices with an entertainment-based intervention. The edutainment interventions use computer-based multimedia to deliver the information as soap-opera/drama components supplemented by voice-overs, personal stories, narration, and animation, information tailored to patient characteristics, and interactive exercises to clarify values (Volk et al., 2008). Jibaja-Weiss et al., 2011) compared routine information about the facts and figures of the disease and choices with an edutainment intervention. Overall, the intervention with the personal stories influenced patients' treatment choices. Participants receiving the intervention with the personal stories component were more likely to be certain about their choice and/or have clearer values over time, and found the multi-media methods to be acceptable and engaging. However, there was mixed evidence that these interventions were differentially effective with those of differing health literacy levels.

Table 3: Reviewed RCT Studies -- Study Characteristics

Authors	Sample	Sample Type	Location	Theory	Aim	Measures
Dillard et al. (2010)	N = 1533	General population	USA	Affective forecasting theory	To use patient stories to promote colorectal cancer screening.	Perceived barriers of screening; risk perception; knowledge; screening interest; time spent reading text.
Volandes et al. (2009)	N = 200	General population	USA	None stated	To examine whether using a video of a patient with advanced dementia could shape future care choices.	Knowledge and experience of dementia; care preference; health literacy; acceptability of video.
Volandes et al. (2009b)	14 pairs of patients and their carer	General population	USA	None stated	To compare concordance of preferences among elderly patients and their carers.	Knowledge and experience of dementia; care preference; health literacy; acceptability of video.
Volandes et al. (2011)	N = 76	General population	USA	None stated	To examine whether using a video of a patient with advanced dementia could shape future care choices.	Knowledge and experience of dementia; care preference; health literacy; acceptability of video.
Winterbottom et al. (2011)	N = 1694	Students	UK	Information processing theory	To investigate the impact of another patient's dialysis story on participants' choices and/or a decision-attribution table de-biases information.	Knowledge and experience kidney disease; hypothetical treatment decision.
El-Jawahri et al. (2009)	N = 50	Patients with malignant glioma (cancer)	USA	None stated	To examine whether using a video of images of patients on three levels of medical care (life-prolonging, basic, and comfort care) for advanced cancer on comfort care preferences.	Preferences for end of life care and CPR; knowledge; certainty with decision; acceptability of video.

Kreuter et al. (2010)	N = 489	African-American women from general population	USA	Information processing and behaviour change theories	To compare the effects of narrative and informational videos on mammography uptake.	Knowledge and experience breast cancer; medical mistrust; perceived physician recommendation; mammography use; beliefs about cancer; perceived barriers mammography; perceived risk; acquisition information; reasoning (counter-arguing); talking to family and friends.
Jibaja-Weiss et al. (2011)	N = 100	Female patients with early stage breast cancer	USA	Communication theories under the rubric of entertainment-education	To evaluate an entertainment-based decision aid for early stage breast cancer surgery in low health literacy patients.	Knowledge of breast cancer; decisional conflict scale; surgery; surgical treatment preference; decisional conflict.
Volk et al. (2010)	N = 450 (n = 149, low literacy; n = 301, high literacy)	Patients eligible for prostate cancer screening	USA	Communication theories under the rubric of entertainment-education	To evaluate an entertainment-based decision aid for prostate cancer screening amongst high and low health literacy patients.	Acceptability and engagement with the PtDA; knowledge of prostate cancer and screening; decisional conflict scale; self-advocacy scale.
Fagerlin et al. (2005)	1 st study, N = 613 2 nd study, N = 875	General population	USA	Information processing theory	To examine whether graphical representations of statistics will reduce the influence of testimonial information on decision making about treatment for angina (surgery/ balloon angioplasty).	Hypothetical treatment decision.

Table 4: Reviewed RCT Studies -- Characteristics of Narrative Content

Authors	Narrative Type	Factual Content	Content of Patient Story	Presentation of Patient Story	Other Features of Patient Story	Study Conditions
Dillard et al. (2010)	First person written narrative	Information obtained from National Cancer Institute online booklet	Patient story described one individual's experience of deciding about screening; no additional factual information	Written patient story integrated into standard information in 4 sections focusing on: feeling uncertain about the decision; barriers to screening; impact bias.	Photograph of narrator included – matched to participants' demographic characteristics.	2x2 design: patient story (present or absent) versus screening type (colonoscopy or virtual colonoscopy).
Volandes et al. (2009a)	Video of patient experience (no verbal dialogue)	Verbal information based on the Functional Assessment Staging (FAST) stage 7a (i.e., criteria for the most advanced stage of dementia)	Dementia patient is shown unable to communicate, in a wheelchair, unable to feed herself.	Video decision support tool presented on a computer (lasting 2 minutes).	A real patient with advanced dementia (80 year old female) and 2 daughters in a nursing home setting were utilised in the video. Video developed in consultation with specialists in dementia, filmed without prompts, and based on publishing filming guidelines.	A verbal narrative or a decision support tool + verbal narrative.

<p>Volandes et al. (2009b)</p>	<p>Video of patient experience (no verbal dialogue)</p>	<p>Verbal information based on the Functional Assessment Staging (FAST) stage 7a, (i.e., criteria for the most advanced stage of dementia)</p>	<p>Dementia patient is shown unable to communicate, in a wheelchair, unable to feed herself.</p>	<p>Video decision support tool presented on a computer (lasting 2 minutes)</p>	<p>An 80 year old female patient with advanced dementia and 2 daughters in a nursing home setting. Video developed in consultation with specialists in dementia, filmed without prompts and based on published filming guidelines.</p>	<p>A verbal narrative or a decision support tool + verbal narrative.</p>
<p>Volandes et al. (2011)</p>	<p>Video of patient experience (no verbal dialogue)</p>	<p>Verbal information based on the Functional Assessment Staging (FAST) stage 7a, (i.e., criteria for the most advanced stage of dementia)</p>	<p>Dementia patient is shown unable to communicate, in a wheelchair, unable to feed herself.</p>	<p>Video decision support tool presented on a computer (lasting 2 minutes)</p>	<p>An 80 year old female patient with advanced dementia and 2 daughters in a nursing home setting. Video developed in consultation with specialists in dementia, filmed without prompts and based on published filming guidelines.</p>	<p>A verbal narrative or a decision support tool + verbal narrative.</p>

<p>Winterbottom et al. (2011)</p>	<p>Study 1: written and videotaped 1st and 3rd person narratives Study 2: videotaped 1st and 3rd person narratives</p>	<p>Brief description of factual information about haemodialysis (HD) and continuous cycling peritoneal dialysis (CCPD)</p>	<p>Four hypothetical decision scenarios. Two patients and two doctors describing treatment information, how treatment fits into patients lives and how patients typically make their dialysis decision.</p>	<p>Study 1: written or video (Study 2, video only) narrative presented after basic factual information about HD and CCPD.</p>	<p>In study 1: 1 male and 1 female actor played 2 roles each. In study 2: 2 male and 2 female actors played each of the 4 roles. Narratives developed from the literature and in consultation with renal specialist.</p>	<p>Study 1: 2x2x2 format (written vs. video) x source (patient vs. doctor) x order (HD information vs. PD information). Study 2: 3x2x2x2: decision table (none, before or after story) x order (patient vs. doctor first) x sex of patient (male, female) x sex of doctor (male, female). Control group read only basic factual information in both studies.</p>
<p>El-Jawahri et al. (2009)</p>	<p>Video of patient receiving different types of treatment (no direct narration)</p>	<p>Verbal narrative describing 3 levels of medical care for advanced cancer.</p>	<p>3 levels of care presented, identical to the verbal narrative but with visual images showing patients in various scenarios relating to each of the options.</p>	<p>A 6 minutes video presented on a laptop computer.</p>	<p>Video developed in consultation with cancer specialists, filmed without prompts and based on publishing filming guidelines.</p>	<p>Control (verbal narrative alone) versus intervention (video after verbal narrative).</p>

<p>Kreuter et al. (2010)</p>	<p>First person stories from cancer survivors</p>	<p>Not applicable</p>	<p>Both videos both addressed 11 key messages about breast cancer. Video 1: personal stories from African American breast cancer survivors, Video 2: didactic, expository form from an African American woman, cancer survivor.</p>	<p>Videos presented via a mobile communication research facility in the community.</p>	<p>Video 1: 57 short stories elicited from 29 cancer survivors. Edited to form narrative about risk, talking about cancer and mammography screening. Video 2: Material developed from video 1 and presented by a single narrator with images, photos, graphics and music. Videos piloted for equivalence.</p>	<p>Comparison of 2 videos.</p>
<p>Jibaja-Weiss et al. (2011)</p>	<p>Storyline conveys decision making process in brief soap opera style videos</p>	<p>Usual care</p>	<p>Factual information about surgery options and other treatments presented in interactive learning modules component of ptDA</p>	<p>Decision making process for making a surgery decision presented in the format of didactic soap operas</p>	<p>In the DA the storyline does not reveal what surgery option the main character chooses; a values clarification exercise is included. DA conforms to IPDAS criteria.</p>	<p>Intervention: a computerised interactive multimedia DA utilising entertainment (soap opera episodes and interactive learning modules) and usual care versus control: only usual care.</p>

Volk et al. (2010)	Main character conveys factual information and decision making process in small soap opera style videos.	Control receive: an audio booklet with no values clarification, entertainment component, testimonials or values-clarification exercise	Factual information about prostate cancer and screening presented in the format of didactic soap operas and interactive learning modules.	A computer based decision aid based on the Edutainment Decision Aid Model (EDAM).	In the DA, ethnicity of main character tailored to the viewer; celebrity testimonials and values clarification exercise included.	Intervention: an interactive computer based decision aid versus control: an audio booklet.
Fagerlin et al. (2005)	First person written narratives	A hypothetical scenario and 2 treatment options presented to all patients. Each treatment option differed in terms of their arduousness and success rate.	The experience of former patients with each of the treatment options was presented with the scenario.	Written patient narratives with the number of narratives varied to be representative or non-representative of cure rate.	Information in the narratives was repetition of that presented in the scenario so no new information was supplied in the narratives. Study 1: A pictograph and trade-off quiz were also presented to some participants.	Study 1: 2 (representative vs. non-representative narratives) x 2 (pictograph and quiz vs.. no pictograph or quiz). Study 2: 2 (pictograph v no pictograph) x 2 (no trade off quiz vs.. trade off quiz) [all participants received non representative narratives]

Summary

There is limited but increasing evidence of the impact of personal stories within interventions on people's healthcare decision making. All studies found that presenting information with a personal story component affected people's judgments and choices differently from presenting factual information alone. There was variability in the way personal stories were sourced, constructed, delivered, integrated within the intervention, and evaluated. Additionally, the study purpose, and therefore the function of the personal story, varied in terms of investigating either biases in decision making, health behaviour change, or participant engagement with information. As a result, the synthesis was not able to identify the active ingredients of the personal story that may enhance, or limit, the effectiveness of patient decision aid interventions.

However, there were some similarities across the experimental and real-world studies suggesting that people use both personal story and factual information when making healthcare decisions, and that there is an interplay between the processing of personal story and factual information with subsequent attention to information, evaluations and decisions. It was unclear how this interplay could be maximised to ensure patients' healthcare decision making was supported rather than biased. There was little evidence that personal stories were associated with enhancing health literacy over and above the other component parts of a decision aid (Clement et al., 2009).

c) Emerging Issues/Research Areas in Evidence Base

The emerging issue from the current evidence base is that it is unclear whether or not personal stories are a necessary ingredient of patient decision aid interventions. Decision aid interventions are evidence-based resources designed to enable patients to engage actively with the healthcare decision in order to make an informed decision. Personal stories contain complex and detailed information of, usually, one person's experience of an illness and consequences of making a healthcare choice. The narrative both structures and interprets the information so that it makes sense from that individual's perspective, in accordance with his or her views about how their choices and experiences are linked to his or her values. The evidence suggests that people engage differently with information delivered as part of a personal story than from the factual information within patient decision aids. Furthermore, the evidence indicates personal stories change people's judgments of the relevance of the information to themselves and the choices they make in a way that is consistent with models of healthcare behaviour change (Hinyard and Kreuter, 2007). Currently, there is insufficient evidence to ascertain if personal stories add value, or are detrimental, to the effectiveness of a patient decision aid to support people making informed healthcare decisions.

There is tremendous scope to advance understanding of the role of personal stories in patient decision aids on patient decision making and healthcare behaviour change. A pragmatic way forward is for developers to be explicit about the function and rationale of their personal story and its contribution to the decision aid over and above the provision of well-designed information. Essential to the field is evidence that the patient story component is an active ingredient within the patient decision aid, which means assessing its value separately from the other components within a decision aid and identifying measure(s) to ascertain its impact on patients' decision making processes and outcomes. It is possible that patient stories enable decision aid developers to design evidence-based resources that increase healthcare engagement and support patients in making informed decision. However, we need evidence

to identify the active ingredients within personal stories to ensure that they do not bias the healthcare decisions patients make and invalidate patient decision aid resources.

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**APPENDIX:
ORIGINAL CHAPTER E**

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Original Rationale/Theory

Examples of others' experiences with decision making are used for four main reasons:

- to provide factual information to help patients understand the options and their associated outcomes;
- to demonstrate how patients value decisions differently;
- to share a range of opinions; and
- to exemplify the steps others have used to make decisions.

Traditionally, it has been argued that, to achieve informed consent, patients need evidence-based information about outcomes associated with all of the options and an opportunity to weigh up these outcomes in the context of their own values and lives. This approach assumes that information about outcomes is meaningful to patients. However, patients who are unfamiliar with a health state may find it difficult to imagine that health state, and the extent that it may affect their lives. An important part of processing evidence-based information is developing a vivid and authentic picture of the health states under consideration. A primary method that patients use to develop such a picture is to read about or listen to the stories of others who have experienced that state.

Most patients find such stories easier to process and recall than statistics. For example, facts and figures -- such as the mean number of times side-effects occur and the average intensity or severity of these side-effects -- are harder for many patients to understand than the stories of patients who have experienced these side-effects. The stories of patients who have actually experienced a health state are seen as having a level of authenticity that health professionals who have never experienced that health state cannot provide, even if they have particular expertise in that health state. For example, women with breast cancer suggested that the severity of lymphoedema was under-represented for many years by health professionals, who did not measure it correctly, or follow-up women for long enough to perceive the true prevalence of lymphoedema-related distress.

Furthermore, provision of balanced examples of how and why other patients have chosen certain options is seen as important for effective decision-making. It allows patients to learn not only what others choose, but also the reasoning or values behind these choices, with the different cases reinforcing the notion that decision-making is variable. As well, stories can exemplify the steps or process others have used in making the decisions. Whether or not stories are provided in patient decision aids, patients are likely to seek individuals who have

experienced the decision.

Although we know very little about the role of patient stories in patient decision aids compared to the many other sources of patient experiences available, the inclusion of these stories in patient decision aids appears to be widely supported. However, a number of concerns about the inclusion of patient stories have been expressed. These include:

- The stories of a few individuals can never represent the experience of the majority, and yet these may over-ride consideration of more representative facts and figures.
- The selection of patient stories may provide a biased view. For example, only patients who are articulate, have strong motivations to tell their story, and speak the same language may be included. As well, even a “balanced.” presentation of views can potentially give false impressions that there is an equal split in opinion about treatment, when in fact 90% of patients recommend or accept a particular option.
- Patients who have chosen a particular option are committed to supporting that option, for fear of regret. This has been called “cognitive dissonance” (i.e., the description of negative experiences arising from an option would be in conflict with the patients’ desire to believe that they had chosen the best option). Thus, the accounts of any patients who have already chosen a treatment option are likely to be biased.
- Long-term experiences when the disease is life-threatening can only be provided by patients who survived; by default, the experiences of those who benefited less are not available because these patients are no longer alive.
- Some patients’ stories may be elicited by unethical means. For example, drug companies may pay patients to provide a positive description of the outcomes of certain treatment options.
- There is often a mismatch between the rigor involved in the collection and presentation of evidence-based information about the effects of treatments, and limiting “patient stories” to a very few accounts from patients who are available, photogenic, or sufficiently literate to share their experiences.

Finally, appropriate, rigorous methods exist for researching and selecting patients’ experiences with health and illness (e.g., Popay, Rogers, & Williams, 1998) to ensure that the stories are evidence-based, cover the full range of experiences, disclose the context in which the decision was made, minimize the potential limitations of using patient stories, and maximize their value. With attention to the rigorous methods used to select patient stories, patients should find a perspective akin to their own that can facilitate rather than impede high quality decision making.

Original Evidence

Patients’ Decision Making Needs

A cross-sectional telephone survey of 635 Canadians was conducted to describe decision-making needs of patients when faced with complex health decisions characterized by the need to balance benefits versus risks of various options (O’Connor, Drake et al., 2003). Over

half of the participants reported obtaining support and information about what others decided. Of these, most cited their personal doctor (32%), friends (29%), other patients (27%), or other doctors (27%). Respondents were also presented with eight factors (including knowing what others decide or recommend) that could be considered essential criteria for concluding that a decision is satisfactory. Interestingly, all factors were strongly endorsed by participants (>89%), except for the factor referring to “others’ experience” (22%) (O’Connor A, personal communication, January 26, 2004). These observations suggest that, although patients value and desire others’ experiences to be included in patient decision aids, other aspects of patient decision aids -- such as knowing the main options and their pros and cons, or being satisfied with the choice made -- are considered more important patient decision aid components.

RCTs Involving Patients Facing Actual Choices

Of 29 individual patient decision aids evaluated in 34 RCTs in the Cochrane Review, 19 were available for review of their content (O’Connor, Stacey et al., 2003).

- 74% (14 of 19) included examples of others’ experience. Of these 14, 8 provided testimonials, 4 provided examples of balance scales completed by others, 1 used group discussion, and 1 supplied regression weights.

Available evidence concerning inclusion of others’ experience in patient decision aids is sparse, though increasing (Ubel, 2002).

Use of Narratives

The use of narratives can make information more salient, easily imaginable, memorable, and more readily evaluated (Price & Czilli, 1996; Sanfrey & Hastie, 1998; Satterfield, 2001). Michielutte et al. (1992) reported that a narrative style of text significantly improved comprehension, particularly among readers with low literacy skills.

Use of Patient Testimonials

Ubel, Jepson & Baron (2001) investigated whether the inclusion of patient testimonials in patient decision aids affects patients’ treatment choices. Prospective American jurors were presented with hypothetical statistical information about the percentages of angina patients who benefit from angioplasty and bypass surgery (50% and 75%, respectively). This information was supplemented by written testimonials from hypothetical patients who had benefited or had not benefited from each of the two treatments. The numbers of patients benefiting/not benefiting were varied to be either proportionate or disproportionate to the statistical information. It was found that the percentage of participants expressing a preference for bypass surgery over angioplasty varied from 58% (among participants receiving no testimonials) to 30% (among participants receiving 1 positive and 1 negative testimonial for each treatment), even though all participants received identical statistical information about the effectiveness of the treatments. It was concluded that inclusion of written patient testimonials, when presented with statistical summary data on treatment effectiveness, significantly influenced hypothetical treatment choices. The number of testimonials in favour of either option strongly influenced choice.

Current Research

Since the majority of studies concerning the inclusion of others’ experiences have been conducted with non-patient populations, outcomes of similar studies within clinical

settings still need to be ascertained. Associate Professor Peter A. Ubel and co-investigators are currently conducting a study to delineate the effect of patient testimonials on patients' treatment choices, and to find ways to minimize the chance that testimonials will distract patients from probabilistic information.

Simon Whitney and Michael Crouch, funded by a K-08 Career Development Award from AHRQ, are currently conducting a randomized controlled trial of a patient decision aid for statin therapy ("Statin Therapy Informed Choice"). In the self-administered version, a section entitled "What would my experience be like if I took a statin cholesterol medicine?", ten "mini-stories" depict the main foreseeable outcomes of the statin therapy decision. The likelihood that an individual's experience would be like that of the person in each mini-story is provided in terms of odds and "chances in 1,000" (based on data from the large statin trials). Thus, the investigators have tried to combine the hypothesized value of stories (for making possible scenarios seem more real) with a fact-based estimate of the likelihood that the stories are applicable to the individual.

In conclusion, the current evidence about this topic is limited and conflicting. It remains to be clarified whether it is possible to identify a 'best strategy' for the inclusion of others experiences in patient decision aids. It is likely that different conditions and types of decision will require different combinations of material, suggesting that the evidence will never be applicable to all, even if based on appropriate clinical populations. However, common issues include how to present balanced patients' stories representing each outcome, and how to integrate the priorities expressed in the patients' stories with the statistical information about health outcomes.

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