Integrating a Patient Values-based Dialysis Aid into Nephrology Care: Impact on Patient/Nephrologist Communication and Patient Preferences

Meg Wise, MLS, PhD;[1] Dorian R Schatell, MS;[2] Kristi Klicko,[2] Betty Chewning;1 PhD; William Aggar, MD;[3] Akhtar Ashfaq, MD,[4] Micah R Chan, MD;[5]

[1] Sonderegger Research Center, School of Pharmacy University of Wisconsin • [2] Medical Education Institute• [3] Opko Health n • [4] Division of Nephrology, School of Medicine and Public Health, University of Wisconsin-Madison

BACKGROUND AND SPECIFIC AIMS

Hearing a nephrologist say, "You might need dialysis" is difficult for patients—who fear they will face a dismal life tethered to a machine or imminent death—*and* for nephrologists, who often consider giving "bad news" about dialysis to be the worst part of their jobs. Fear may be due to the notion standard, thrice-weekly in-center hemodialysis (ICHD) is the only choice. ICHD, used by 89% of US dialysis patients in has harsh side effects, loss of work and social roles. By contrast, home dialysis—e.g. peritoneal dialysis (PD), daily home hemodialysis (HHD), and nocturnal home hemodialysis (NHD) yields better quality of life. There are tradeoffs. Home dialysis requires patient-self-management, training, some control over the home environment, and a care partner (for HHD). Thus, the overwhelming use of ICHD is a mystery. Medical decision-making driven by the patient's values, hopes and aspirations been found to results in greater satisfaction with the treatment than didactic information. However, nephrologists, like other physicians, are not trained in this decision-making style. Values-based patient decision aids for cancer and other illnesses have helped patients decide on complex medical treatments when options entail tradeoffs between competing values. We hypothesized that My Life, a values-based shared decision aid would increase focus on patient's values and treatment preferences, ease the dialysis

METHODS

Recruitment: Women, age ≥50 years, reporting bladder or bowel incontinence in the 2016 Survey of the Health of Wisconsin (SHOW) were invited by letter, recruited by phone. They received a pre-interview packet with a fact sheet, descriptions of the proposed intervention formats, and the interview questions.

Data : 30-minute audio-recorded phone interview, transcribed verbatim, asked women ***how and why*** they would rank their preference for a:

- Single in-person lecture & handouts (2 hrs.)
- Small-group 3-session workshop with problem-solving, socialization, behavioral support & handouts (6 hrs.)
- Digital program: information, communication and self-tracking tools (Time: You decide)

Analysis: Verbatim transcripts were analyzed with grounded theory, a systematic, iterative inductive method, and then mapped to SHOW survey data to develop a conceptual model.

RESULTS

Sample: 41 women were invited; 23 (56%) enrolled. The mean age was 67 (± 11), range 51-93.

	N (% of 23)
Non-Hispanic White, n (%)	20 (87)
Married	14 (61)
Education at least college degree	10 (43)
Income < 200% Federal Poverty Level	5 (22)
Job and/or Caregiving Responsibilities	14 (61)
BMI: Overweight (25 - 29.9); Obese (≥30)	17 (73)
Bladder **and** bowel incontinence	11 (48)
Internet use for health information	15 (65)
Engaged in Health Education Programs	16 (70)

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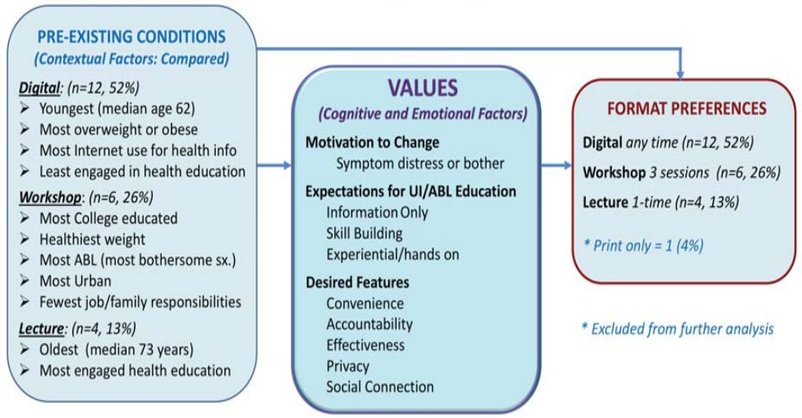
Conceptual Model: Factors influencing format preferences



FORMAT PREFERENCES

Modality	Benefits	Drawbacks: Lack of…
Digital **First** **N=12 (52%)**	***Convenience:*** "If I want to do it at midnight, I can do it at midnight without worrying about missing something." ***Privacy:*** "Nobody sees you." ***Self-directed learning:*** "If I don't understand something I can go back through it again." ***Social connection:*** "The [blog] would be helpful to realize that it's not just you."	***Accountability:*** "It might be too easy not to do [or] complete because you get distracted." ***Effectiveness/Skill-building:*** "You can read all you want. You still don't know if you're doing it right." ***Social connection*** "You aren't going to have human contact." ***Technology:*** "I don't have computer access… I am not computer savvy."
Workshop **Second** **N=6 (26%)**	***Social connection:*** "Bumping ideas off other individuals is helpful in situations like this." ***Accountability:*** "Like weight watchers and going to the gym with your buddy." ***Effectiveness/Skill building:*** "Good way to teach women how to change these things." ***Experiential learning:*** "I get more out of the hands-on approach."	***Convenience:*** "By having three different workshops it means three different times." ***Privacy:*** "Sitting around a table eye to eye with people. I'd feel vulnerable" ***Comfort:*** "I'm not comfortable speaking in front of people. I didn't take my Dale Carnegie course." ***Motivation/Salience:*** "Six hours would be overkill."
Lecture **Third** **N=4 (13%)**	***Information-only/Traditional education:*** "I like listening. I could sit and take notes." ***Privacy:*** "The anonymity—sitting in a big auditorium." ***Convenience:*** "One and done. It's just a small commitment, more doable right now.	***Social connection:*** "In big groups I get intimidated. I will listen but not tell my opinions. I feel very isolated." ***Privacy:*** "Being seen by someone you know." ***Effectiveness/Skill building:*** "I would probably get more out of the workshop"

VALUES driving format preferences

	Digital	Workshop	Lecture	Total
Motivation to Change *	n (% of 12)	n (% of 6)	n (% of 4)	n (%/23)
Low symptom distress	4 (33)**	-	2 (50)	6 (27)
High symptom distress	2 (17)	4 (67)	-	6 (27)
Expectations for Education				
Information alone is enough	7 (52)	0 (0)	2 (50)	9 (41)
Experiential / Social learning	5 (47)	6 (100)	2 (50)	11 (50)
Skill building	3 (25)	6 (100)	0 (0)	10 (45)
Desired format features				
Convenience	11 (83)	0 (0)	4 (100)	15 (68)
Privacy	8 (67)	1 (17)	1 (25)	10 (45)
Effectiveness	2 (17)	6 (100)	2 (50)	10 (45)
Accountability	2 (17)	6 (100)	0 (0)	8 (35)
Facilitator-guided	2 (17)	6 (100)	4 (100)	12 (54)
Self-directed learning	9 (75)	0 (0)	0 (0)	9 (41)
Connection / community	5 (47)	6 (100)	2 (50)	13 (56)
Printed packet	2 (17)	6 (100)	4 (100)	10 (45)

* Women were not asked about symptoms. 12 self-disclosed their distress.
** Purple text notes difference

Digital proponents noted low symptom distress, valued convenience, privacy, and self-direction over accountability. Some suggested a hybrid digital/in-person format.
Workshop proponents noted high symptom distress, valued experiential/social learning, effectiveness, skill-building and accountability.
Lecture proponents noted low symptom distress, valued convenience over effectiveness or social connection. Some suggested optional small-group breakout sessions.

CONCLUSIONS AND PRACTICE IMPLICATIONS

The majority of women with bladder or bowel leakage would choose a digital format for continence self-management education. As the U.S. population age increases, so too will incontinence and comfort using the Internet. Digital formats hold promise to fill the growing gaps in access to primary healthcare and uncertain Medicare funding. To foster behavior change and accountability, a digital intervention should provide opportunities for experiential, social and guided learning; tools to build skills, set goals and track progress, as well as tool, and.

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