



# Friedreich's ataxia patients and caregivers information seeking behaviour

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**Objectives:** (1) to improve the quality of the information that Friedreich's ataxia (FRDA) patients and care-givers receive after diagnosis; (2) to provide a reliable tool to spread these information.

**Materials and Methods:** Thirty-four FRDA patients and 45 informal unpaid care-givers were interviewed by self-administered questionnaire about their information seeking behaviour.

Participants could choose up to 4 options regarding the information sources: "FRDA specialist", "Primary care physician", "Informal non specialist medical source of information" and "Media". Interviewees specified their personal order of importance from 1 (most important) to 5 (less important) for every consulted source. The level of expectation and satisfaction for every information source were assessed instead using a reverse scale from 5 (most important) to 1 (less important) and we considered value >4 as a high score.

Interviewees could choose the following as tools of information proposed: "information booklet", "FRDA Center website", "website managed by patients and/or care-givers", "FRDA referral Center toll free number".

**Results:** The main source of information was the FRDA specialist, and in this group the neurologist was the most frequently consulted source. Seventy-four patients showed a high level of expectation in the neurologist, 65% in the media; 68.5% of care-givers in the neurologist and 42% in the media. Among patients 62% showed a high level of satisfaction with the neurologist and with the media; 60% of care-givers with the neurologist and 33% with the media.

The first three types of information searched for by patients in order of importance were "general information" (65%), "clinical course" (15%) and "associated symptoms" (6%); among care-givers, "general information" (38%), "clinical course" (31%) and "existing therapies" (11%).

Contradictions were found mainly between "media" and "neurologist" (26,5% among patients, 13,3% among care-givers). In most cases the "neurologist" was the source that provided clarifications.

Regarding the desired information, most patients and care-givers focused on the existing and experimental therapies.

Most participants in both groups would receive information via a FRDA referral Center website.

	Patients	Caregivers
N.	34	45
Gender (M/F)	16/18	19/26
Age (mean; SD)	29.9 [15.6 - 48.4; 8.5]	55.5 [32.4 - 83.5; 9.5]
Disease duration (mean; range; SD)	16.1 [5.7 - 34.4; 6.7]	-
Age of onset (mean; range; SD)	13.8 [2.4 - 33.6; 7.1]	-
Age at diagnosis (mean; range; SD)	19.2 [5.4 - 45.3; 8.6]	-
Education (mean; range; SD)	14.3 [8.0-18.0; 8.5]	11.7 [5.0 - 18.0; 4.5]
FARS score (mean; range; SD)	53.0 [18.0 - 85.0; 22.3]	-
SARA score (mean; range; SD)	19.1 [4.0 - 32.0; 9.0]	-

TABLE 1: DEMOGRAPHIC AND CLINICAL DATA

	Patients		Care-givers	
	FC, FC%	SS, SS%	FC, FC%	SS, SS%
<b>FRDA specialist</b>	14, 41.2%	31, 91.2%	27, 60.0%	43, 95.6%
<b>Neurologist</b>	12, 35.3%	30, 88.2%	23, 51.1%	39, 86.7%
<b>Geneticist</b>	1, 2.9%	10, 29.4%	1, 2.2%	16, 35.6%
<b>Pediatrician</b>	1, 2.9%	2, 5.9%	3, 6.7%	8, 17.8%
<b>Primary care physician</b>	6, 17.6%	11, 32.4%	7, 15.6%	18, 40.0%
<b>Informal non specialist source of information</b>	6, 17.6%	20, 58.8%	3, 6.7%	14, 31.1%
Family	6, 17.6%	16, 41.1%	2, 4.4%	9, 20.0%
Friends	0, 0.0%	6, 17.6%	1, 2.2%	6, 13.3%
Acquaintances	0, 0.0%	1, 2.9%	0, 0.0%	3, 6.7%
<b>Media</b>	8, 25.5%	32, 94.1%	8, 17.7%	33, 73.3%
Internet	6, 17.6%	30, 88.2%	4, 8.9%	29, 64.4%
Printed material	2, 5.9%	6, 17.6%	4, 8.9%	15, 33.3%

TABLE 2: SOURCE PREFERENCE FOR INFORMATION IN FRDA

FC: First Choice; SS: Source Selected

**Discussion:** As adequate information supply is considered to be a part of good medical care and support, it is essential to explore the information seeking behaviour of FRDA patients and care-givers in order to gain more insight into their needs, indications for better ways/means of communication and a tailored information supply.

**Conclusions:** Our study provides useful data on the information seeking behaviour in FRDA, with the opportunity to improve the therapeutic alliance among neurologists, patients and care-givers.